

MIDTERM EVALUATION CHORNOBYL CHILDHOOD ILLNESS PROGRAM

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ACRONYMS AND FOREIGN TERMS

CEE	Central and Eastern Europe
CCIP	Chornobyl Childhood Illness Program
CDI	Children's Depression Inventory
CDIE	Center for Development Information and Evaluation
ENI	Europe and the New Independent States
feldsher	Physician assistant, medic
FNA	Fine needle aspiration
FY	Fiscal year
GOU	Government of Ukraine
IEM	Institute of Endocrinology and Metabolism
MCi	megaCuries
MEDS	Monitoring, Evaluation and Design Support Project
MOH	Ministry of Health
MOE	Ministry of Emergencies
MOU	Memorandum of Understanding
MSCI	Medical Services Corporation International
NGO	Nongovernmental organization
NIH	National Institutes of Health
NIS	New Independent States
oblast	Provincial administrative unit (region)
PATH	Program for Appropriate Technology in Health
raion	District administrative unit
R4	Results Review and Resource Request
SO	Strategic Objective
TSH	Thyroid stimulating hormone
UAHC	Ukrainian–American Health Center
UNESCO	United Nations Educational, Scientific, and Cultural Organization
USAID	United States Agency for International Development

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EXECUTIVE SUMMARY

A. BACKGROUND

Health care providers in Ukraine, assisted by the United States Agency for International Development (USAID), have embarked on a groundbreaking effort to improve the early detection and treatment of thyroid cancer in children. The 1986 Chernobyl nuclear catastrophe released an enormous quantity of radioiodines into the atmosphere. This was followed by an outbreak of childhood thyroid cancer in the surrounding areas. Children born after 1986 did not have an increased incidence of thyroid cancer. However, thyroid cancer in children of southern Belarus began to increase in 1990, and today there are more than 1,000 cases in Belarus and northern Ukraine. Moreover, malignant as well as benign thyroid neoplasms are expected to continue to arise in these exposed children well into their adult lives. Prior to the Chernobyl accident, the incidence of thyroid cancer in Belarus and Ukraine was the same as that found in other European countries and the United States. The size of the increase in the number of childhood thyroid cancers is too great to be explained by increased awareness. Based on the geographic and temporal distribution of the cases, there is strong evidence that the increased incidence of childhood cancer is caused by radiation exposure as a result of the Chernobyl nuclear reactor accident.

Fortunately, thyroid cancers are relatively easy to treat, especially if detected at early stages. The vast majority of children treated with drugs of current choice have excellent long-term survival rates. Studies in several countries have also found that children with cancer need psychological support.

B. USAID SUPPORT

In May 1988, a consortium led by Medical Service Corporation International (MSCI) began work on USAID's three-year Chornobyl Childhood Illness Program (CCIP). Numerous Ukrainian counterparts are involved in the program, which seeks to improve access to and the quality of thyroid cancer and psychosocial trauma screening, diagnosis, and treatment. CCIP has worked to enhance the cost effectiveness and sustainability of providing thyroid and psychological care to children. The project is primarily active in three of the six most radioactive-contaminated regions in Ukraine: the Volyn, Rivne, and Zhytomir oblasts. The Cherkassy Oblast was chosen as the fourth pilot region because many families were relocated there after having been forbidden to reside in zones with heavy radioactive contamination.

Using a holistic approach to the management of children with physical and mental problems, the MSCI team has created an integrated development approach to address project objectives. The project emphasis is on enhancing thyroid cancer and

psychological services in both preventive and therapeutic care. Project activities have reinforced outreach screening for early cancer detection in more treatable stages through use of clinical and ultrasound examination. The project has addressed psychosocial problems in children and their families through implementation of trauma manifestation outreach screening programs. Work has also included assistance in setting up the screening database system.

C. PURPOSE OF THE EVALUATION

The objectives of the evaluation described in this report were to

- identify, quantify, and document the outputs and results to date of the CCIP, including success stories and lessons learned according to objectives of the project, as well as in relation to the applicable goals under Strategic Objective 3.2b;
- assess the CCIP and identify factors contributing to its effectiveness, including current changes in performance and results as well as institutional changes that formed the basis for future results, and provide an informal cost–benefit analysis if feasible in the time allotted;
- identify potential linkages with other USAID health programs and other international donor programs;
- identify the potential for roll-out and national sustainability of system changes developed and tested in pilot sites;
- identify barriers to successful project implementation, as well as gaps or areas in need of further work to strengthen the project and achieve its objectives; and
- recommend effective strategies and potential changes for project implementation in subsequent years.

D. METHODOLOGY

A 3–person evaluation team consisting of a medical anthropologist, endocrinologist, and psychologist spent 2 weeks in-country between September 10–23, 2000. The team reviewed documents, made field visits to the four program oblasts, and interviewed key informants in depth from all relevant Ukrainian and U.S. organizations. Analysis and interpretation of findings then followed, and a draft report of findings and recommendations was presented before departure from Ukraine.

I. MAJOR CONCLUSIONS AND RECOMMENDATIONS

A. SUMMARY OF MAJOR FINDINGS

The following major findings are based on an evaluation of the program's achievements in light of the Congressional mandate to "establish, or continue, cost-effective and sustainable programs in Ukraine to screen and treat childhood mental and physical illness related to Chernobyl radiation."

- **Screening.** A comprehensive system was established to screen for both physical (thyroid cancer) and mental problems, representing a holistic approach to childhood illness. The size and location of the target population—children between the ages of 12 and 18—was defined.
- **Improvement of thyroid cancer and psychosocial trauma management.** Up-to-date thyroid and psychosocial screening protocols and screening data collection and analysis tools were developed. To date, the program has provided refresher training for 260 physicians and psychologists from pilot regions in ultrasonography, computer applications, and advanced psychological screening and clinical tools.
- **System changes in thyroid cancer and psychological screening provision.** Four Ukrainian–American Health Centers (UAHCs) have been established and equipped in the Volyn, Rivne, Zhytomir, and Cherkassy regions. Each center is the base for a mobile screening team and a focal point for the regional screening program. Portable ultrasound and other diagnostic equipment have been purchased to outfit several minivans, which are used by CCIP and Ukrainian professionals to perform screening and diagnostics on a regular basis in rural areas. The program is also developing community-based and referral systems for psychosocial services for children and their families affected by the disaster.
- **Numeric goals.** The program is currently about 20 percent of the way toward the achievement of its stated numerical goal of screening 100,000 children. Due to the way the mobile teams work, the number screened for thyroid cancer and psychological problems is essentially the same. Twenty percent of examined children have psychological trauma such as depression. On the average, 6 percent of examined children have been found to have thyroid abnormalities of mild and severe stages. Correlation between thyroid abnormalities and psychological manifestations are found in 10 percent of examined children.

- **Referral system.** Improvement is needed in follow up of patients who are referred for evaluation of significant thyroid ultrasound abnormality, as well as for psychosocial treatment. The report makes recommendations for such improvements.
- **Sustainability.** The legacy of the CCIP should be to strengthen the capacity of Ukraine for managing thyroid cancer, specifically in the screening, diagnosis, and treatment of thyroid cancer, and in related psychosocial problems. This strengthening should occur at the oblast health-department level, and it should work to ensure that adequate technical capacity can be found in oblast institutions that manage thyroid cancer and related psychosocial problems. Four ideas about ways to sustain program activities beyond the life of the program are considered.

B. RECOMMENDATIONS

Achieving Screening Objectives: Need for No-Cost Extension

USAID should consider extending the program at no additional cost for a fourth year. A great deal of time and effort have been spent establishing mobile teams and getting them to operate at current efficiency, as has already been documented. It would be a waste of funds already invested to end the project in May 2001 before screening and referral goals are met, given that it now seems possible to meet these goals without additional funds.

Achieving Screening Objectives: Assisting Rivne

CCIP is currently about 20 percent of the way toward achievement of its stated numerical goal of screening 100,000 children at least once during the course of the activity (the number screened for thyroid cancer and psychological problems is essentially the same because of the way the mobile teams work). More than 50 percent, or 54,000, of all at-risk children targeted nationally by CCIP live in Rivne. From the outset, Rivne targeted six northern raions, whereas other CCIP oblast partners targeted three raions. The six raions in Rivne are also areas of iodine deficiency and endemic goiter. Despite its higher burden, Rivne partners are working with the same resources as everyone else.

There are two ways to help Rivne, and CCIP overall, achieve numerical screening goals: one is to provide the Rivne program with a second mobile team by purchasing an additional vehicle and equipment, and staff training; another is to borrow a vehicle and equipment from another CCIP program oblast after it meets its screening objectives.

The first option is more feasible than the second. Rivne CCIP staff are already requesting a second mobile team to achieve its higher numerical goals. CCIP should be financially capable of meeting this request. In addition, importing equipment now should take far less time than earlier in the project, and costs would not be great (\$23,000 for equipment and \$7,000 for a vehicle). No additional staff training would be necessary because Rivne already has 8–9 trained ultrasonographers and an even greater number of trained psychologists. Other additional costs would be in the form of per diems, twice the current

rate. Therefore, the payoff in additional numbers of children screened would far exceed the costs of making it happen.

Of course, this option is only feasible if the project runs for a fourth year. Its feasibility is increased to the extent that there is a realistic sustainability plan in place that would extend program activities beyond the life of the program.

Recommendation

The Rivne UACH should be provided a second vehicle, ultrasonography machine, and computer so that it can operate a second mobile team and therefore meet higher screening objectives in that oblast.

Rate of Screening

The current system for increasing the number of children screened is to pay mobile team members 20 cents for every child screened above and beyond the original goal of 30 per day. This is a kind of per-diem stipend for team members' work in rural areas considered beyond their regular duties. The idea was to raise the rate to 60 children per day, thereby making up for the program's delayed start-up of screening by mobile teams. The delay occurred because it took longer than planned to establish the infrastructure for screening programs within the health care system. The latest reports from oblasts indicate that some teams are screening 90 children per day, no doubt to earn more money. The evaluation team, as well as CCIP/Kyiv staff, is concerned that tying payment (in the form of per diem) directly to "output" runs the risk of compromising the quality of both thyroid cancer and psychosocial screening.

The number of children screened by psychologists on the mobile teams is essentially the same as the number screened medically. Psychologists to date have conducted important crisis interventions but have found it difficult to get children to follow up on referrals and seek psychosocial help elsewhere. Further, psychologists already believe they do not have time to handle any more children than they now have. Therefore, a cash incentive scheme that tempts busy workers to take on more children than they can handle should be avoided.

Recommendation

Members of mobile teams should continue to receive a modest per diem stipend for what amounts to additional work, but this should not be linked directly to the number of children screened over 60 per day. The team believes that a figure around 50–60 per day is reasonable; in fact, this rate represents about 20 more per day than stipulated by existing Ukrainian health regulations for ultrasonography, based on existing guidelines providing for 20 minutes per detection/diagnosis. Fifty to sixty screenings per day will give doctors and psychologists enough time to do their jobs properly and without undue hurry that could lead to a compromise in quality. Greater emphasis should be placed on follow-up diagnosis and treatment than on accomplishing numbers of screenings.

Improved Referral Follow Up

Only one thyroid cancer has been detected as a result of the screening to date in the 20,000 children screened by ultrasound by CCIP. Data from the National Cancer Institute–Institute of Endocrinology and Metabolism (IEM) screening program in Ukraine suggest that a much larger number of cancers, perhaps as many as 36, should be found in this sample of 20,000. The mandate of CCIP is to detect and manage thyroid cancer in the targeted population. Thyroid cancers have not yet been diagnosed in the number expected. The reason for the lack of diagnosis is that fine needle aspiration (FNA) biopsy has been performed on only a very small number of children with nodules of 1 cm or larger.

Recommendations

A major obstacle to program success lies with the ability to follow up with patients who are referred for deeper evaluation of significant thyroid ultrasound abnormality. To improve the follow-up diagnosis and ensure that thyroid cancer cases are not missed, the following actions are recommended:

- Training should be provided so that each oblast will have the capacity to perform ultrasound-guided FNA biopsy, at least at one health institution in each of the four oblasts of CCIP assistance. The IEM should be able to provide such training.
- Each UAHC should incorporate a pediatric or adult endocrinologist into the funded team to improve the follow up of referred children with thyroid nodules.

It is especially important that each UAHC obtain follow-up information on all children with nodules of 1 cm or larger. The retrieval of this information is essential.

Psychosocial Findings and Recommendations

Training

Training provided in the psychosocial area has been highly effective. Future scheduled training should be completed and should emphasize cost management through use of the most effective and practical training. The spread effect of training school psychologists, nurses, youth service workers, and others will greatly enhance program sustainability. These individuals may have the best chance of providing ongoing services to children in rural areas. For example, Red Cross nurses who make home visits can develop rudimentary counseling skills that will help families, teachers, and school psychologists identify and work with troubled children.

One trainer in particular, a clinical psychologist, was frequently cited by participants as helpful. The psychologists believed that given their status as developing professionals,

they would benefit significantly from the experience of a psychologist with clinical training who could help them with actual case material. This information should be used in planning future training sessions; perhaps a balance between training needs and the cost of multiple overseas consultants can be found by focusing future training on the most effective methods and trainers.

The design and implementation of the training program was carried out by social work educators, psychologists, and counselors. The social work component has provided important benefits given the ecological viewpoint in Ukraine that sees the individual not as an isolated unit but as part of a social system. This viewpoint underscores the importance of the work of the mobile psychologists. In addition, the social work educators evaluated their training with pretest and posttest data. More specific evaluation is needed of other types of training as well.

Referral

Efforts must continue to improve the psychosocial referral system and to facilitate feedback to psychologists and administrators on the outcome of referrals. This feedback loop will facilitate more effective interventions. Secretaries in the UAHC centers are in the best position to obtain and compile this information. It is recommended that the issues surrounding the complex referral systems and the lack of systematic feedback and coordination between them be made a priority as soon as possible.

Although costly, the decentralization of services out of central cities in the oblast raions will be most effective in the area of service delivery. This approach can be studied more closely in community-based models. For example, one idea would be to use professional psychologists as consultants and referral sources for the community-based indigenous professional, such as Red Cross nurses.¹ Service models such as crisis telephone lines and support groups such as Ala-Teen might also be considered.

Public awareness

Efforts are needed to improve public awareness of mental health issues. While this work has begun, much remains to be done in distributing written information at a community level.

Sustainability

Work should also continue to ensure the sustainability of psychosocial programs. For example, alternative funding sources for such programs should continue to be sought from foundations and other nongovernmental sources.

¹ CCIP commented on this: "Although Red Cross nurses (in Volyn) perceived the training very positively, we learned from them that they focus more on elderly single people and invalids. Their contacts with children, unfortunately, are very occasional."

Continued development of the new profession of clinical psychology in Ukraine is another area that will require continued support. This includes support for advancement of professional organizations and lobbying, increased training opportunities, peer supervision, and consultation. Training opportunities are needed for psychiatric nurses, school psychologists, family therapists, and social workers. These fledgling professions, with their enormous impact on services for children in Ukraine, require continued support and development.

Incorporate Changes into Work Plan

To achieve CCIP goals and to greatly increase the number of biopsies of referred children, CCIP should incorporate the evaluation team's recommendations in its current and fourth-year work plan.

II. OVERVIEW AND METHODS

A. RATIONALE FOR USAID ASSISTANCE

The U.S. government has been very concerned about the consequences of the 1986 Chernobyl nuclear power plant accident. The U.S. Congress appropriated \$5 million for “the screening and treatment of physical and mental illness” resulting from this accident. USAID granted \$4 million of this amount to Medical Service Corporation International (MSCI) to administer the Chernobyl Childhood Illness Program. The rest of the money funded other childhood Chernobyl-related activities.

B. RELATIONSHIP AND LINKAGES WITH USAID’S HEALTH STRATEGIC OBJECTIVE

The goal of the thyroid cancer component of the CCIP is to help the government of Ukraine develop and implement a technically sound, high-quality, sustainable program for detecting and managing thyroid cancer in the child victims of Chernobyl who are presently between 12–18 years of age. The objective of the program is to provide Ukrainian health care workers and institutions with the knowledge, skills, and procedures that will enable them to give each child with thyroid cancer a chance to grow up and live a full and normal life.

The goal of the psychosocial illness component of the CCIP is to contribute to community mental health and recovery from the traumatic psychological consequences of Chernobyl through replicable strategies of professional community training and empowerment in mental health promotion.

The CCIP goals are compatible with and support the goals of USAID’s Ukraine Health Strategy and Action Plan, whose primary goal is to “improve (the) quality of life and reduce morbidity in Ukraine’s population.” CCIP objectives specifically support USAID Strategic Objective (SO) 3.2, “Increased promotion of good health and access to quality health care.” They also support Intermediate Result (IR) 3.2.1, “Improved health care services delivery,” in particular, IR 3.2.1.3, “Increased clinical preventive services.” Program elements contribute to technical areas described in the Action Plan, namely health care delivery, promotion of healthy lifestyles, professional education and training, and reducing environmental/occupational risk to public health.

To the extent that a viable sustainability plan is implemented after the life of the program, there may also be contributions to two other areas of the Action Plan: financing and improved legal/policy environment.

C. METHODS OF THE EVALUATION TEAM

A four-person team conducted the evaluation between September 10–23 (the time spent in-country). The team consisted of an anthropologist, an endocrinologist, a psychologist, and a surgeon/health economist. Data-gathering methods consisted primarily of indepth interviews, review of written materials, and observations. The team carried out the following activities:

- Review of documents provided by CCIP; the Monitoring, Evaluation and Design Support Project (MEDS); and USAID prior to field work;
- Review of the relevant thyroid cancer and psychological literature (with assistance by the Center for Development Information and Evaluation [CDIE] in literature review and abstract retrieval);
- Telephone and face-to-face interviews with CCIP staff in the United States;
- Meetings with USAID and CCIP administrators, including MSCI and Counterpoint International staff in Kyiv;
- Field visit to the four oblasts of CCIP implementation, including meetings with administrators, ultrasonographers and other physicians, psychologists, trainees, affiliated organizations, and schools;
- Visit with a mobile team in Rivne to a small, remote village to directly observe as well as interview;
- Discussions with team members, and analysis and synthesis of information.

III. PROBLEMS AND CONSTRAINTS

In its mandate for conducting thyroid cancer screening and psychosocial support, the CCIP would face a unique situation. There is no precedent in USAID or indeed in the United States for a program of thyroid screening by mobile ultrasonography, made even more unprecedented by combining psychological screening for depression with medical screening. Everything had to be invented, at least in terms of practical implementation. Several months were needed to bring together potential partners at the national and oblast levels—the Ministry of Health (MOH), oblast health administrations, various oblast health institutions, and health care providers. Time was also needed to find ways to make psychologists an integral part of the program and to establish an infrastructure for delivering interventions. The course of implementation was developed in discussions with other programs engaged in related work, for example the Red Cross and the United Nations Educational, Scientific, and Cultural Organization (UNESCO).

To date, there have been two significant areas of problems and constraints: delays with the mobile teams and therefore the screening/referral system and follow up of referrals. Because of referral difficulties, an insufficient number of children referred for further thyroid or psychological testing or treatment have actually gone on to the referral point.

A. DELAYS

There were major delays in program implementation during the early months. In a program of only three years' duration, such delays impede progress toward achieving stated objectives. The project is significantly behind schedule in that it has achieved only 20 percent of its projected numerical goal, or about 20,000 children screened out of a goal of 100,000 targeted children, as of the beginning of the third year. But in spite of delays in establishing the screening system, the project nonetheless has made considerable achievements in a matter of months (13 months for Volyn oblast, and 5 months for Zhytomyr).

Delays in starting the screening and referral process have been attributed to the following:

- Time needed to import equipment;
- Obtaining waivers from USAID to buy non-U.S. equipment when such equipment was more appropriate for the program;
- More time needed than anticipated to negotiate memoranda of understanding with the IEM (an effort that was unsuccessful in the end), oblast health

departments, and other local partners due to diverging needs, understandings, and expectations on the part of Americans and Ukrainians;

- Flu outbreaks, summer vacations, and incentive issues, such as finding the optimal level of per diem so that staff (doctors in particular) do not lose informal income while in the field.

Furthermore, both ultrasonography and psychological screening took longer per person screened than anticipated, even apart from related problems such as electricity failures.

CCIP has taken steps to overcome these problems. For example, it has increased per diems for fieldworkers so that adequate incentives are now provided for doctors. CCIP also added a second, and later a third, psychologist to mobile teams to speed the administration of the CDI which, with occasional consultations and even crisis interventions take far longer than the average ultrasonography test. It has also shortened the time required for ultrasonography screening by not saving and storing images that do not indicate a thyroid problem, and it bought portable generators to overcome electricity failures.

B. CONSTRAINTS RELATED TO REFERRALS

Referral follow up for both further thyroid and psychological testing as well as for further treatment has been poor. One reason for this is poverty among families of children referred. Poor families may not be able to afford transport costs to travel to a raion or oblast capital city, nor costs associated with staying there for a period of days or longer. An exception is when one of the systems in place to provide travel vouchers to children officially classified as Chernobyl victims is actually able to provide them.

In addition to financial issues, parents may be skeptical of the findings of the CDI screen and are therefore reluctant to send children away for further testing and a largely unknown treatment process. Boys and men, more than girls and women, are expected to be self-reliant and not dependent on others for help for problems lacking obvious physical symptoms (most of those screened and referred are said by local psychologists to be girls). Parents may feel the same about symptoms such as enlarged thyroids; such conditions are common in areas of endemic goiter, so why should their child travel to a distant town for further tests or biopsies?

Indeed, most thyroid cases referred are not likely to be thyroid cancers; they are conditions related to noncancerous thyroid conditions. What is needed as the next stage for thyroid cancers is biopsy by ultrasound-guided fine needle aspiration (FNA). Yet this requires travel to a distant oblast capital, and usually to even more distant Kyiv.

There are other reasons parents may not send their children on for further psychological diagnosis or treatment. Alcoholic or abusive parents may fear being found out and punished. And assuming availability of some treatment or intervention person in the local community, children and parents alike might feel constrained by lack of confidentiality or

fear of gossip. In villages, everyone knows everyone else; people do not want their personal or family problems to become widely known.

IV. THYROID CANCER IN UKRAINE

A. EPIDEMIOLOGY

The Chernobyl nuclear catastrophe in 1986 released an enormous quantity of radioiodines, including about 40 MCi (megaCuries) of ^{131}I and 100 MCi of short-lived radioiodines. It was followed by an outbreak of childhood thyroid cancer in the surrounding communities. Children born after 1986 did not have an increased incidence of thyroid cancer. Thyroid cancer in children of southern Belarus began to increase in 1990 and there now are more than 1,000 cases in Belarus and northern Ukraine. It is expected that malignant as well as benign thyroid neoplasms will continue to arise in these exposed children well into their adult lives. The increased prevalence of thyroid cancer was observed in Belarus only four years after the accident. Prior to the accident, the incidence of thyroid cancer in Belarus and Ukraine was the same as that found in other European countries and the United States. The size of the increase in the number of childhood thyroid cancers is too high to be explained by increased awareness. Based on the geographic and temporal distribution of the cases, there is strong evidence that the increased incidence of childhood cancer is caused by radiation exposure as a result of the Chernobyl nuclear reactor accident.

The increase in the number of childhood thyroid carcinoma cases in Ukraine after the Chernobyl nuclear accident prompted the development of a registry of thyroid carcinoma cases at the Institute of Endocrinology and Metabolism (IEM) in Kyiv. A study (Tronko et al., *Cancer*, 1999;86:149-156) was conducted on the incidence, age, and gender distribution of thyroid carcinoma in Ukraine at the IEM using statistical reports submitted to the registry from 26 regions of Ukraine. During the five years preceding the Chernobyl nuclear accident, a total of 59 cases of thyroid carcinoma were identified in the birth-to-18-years age group (25 in children up to age 14 and 34 in adolescents ages 15–18 years). Between 1986 and 1997, the total number of thyroid carcinomas in Ukrainian children and adolescents was 577 (358 children and 219 adolescents). Morphologically, the thyroid tumors overwhelmingly were papillary carcinomas, and the majority of these also showed a follicular and/or solid growth pattern. Lymph node metastases and other extrathyroidal spread were common, necessitating total thyroidectomy and lymph node dissections in many patients. The largest number of cases occurred in patients living in areas of thyroid radiation doses of 0.50 grays or higher. The morphologic features of those thyroid tumors suggest that they are aggressive tumors with a high frequency of lymph node metastases, venous invasion, and extrathyroidal spread.

The data from the registry at IEM show a progressive increase in the number of cases of thyroid cancer in Ukraine in children who were ages 0–18 years at the time of the Chernobyl explosion. In 1998, 245 new cases were found, and in 1999, another 250 new cases were found in this age group. In the four oblasts near Chernobyl, the number of

new cases of childhood thyroid cancer (related to the April 1986 accident) is now 50 cases per million children per year. The number of new cases is expected to increase during the next 5 years (Valeriy Tereshchenko, IEM, personal communication). Although some recent data show that the number of new cases in the age group 0–6 is declining, the number of new cases in children 6–18 is increasing, resulting in a net increase.

The National Institutes of Health (NIH) National Cancer Institute, in conjunction with IEM, is carrying out a research study of children ages 0–18 in April 1986 in the most contaminated raions of the Kyiv, Zhytomyr, and Chernigiv oblasts. They are screening a group of 20,000 children from these oblasts. Screening has been carried out in 11,000 by ultrasound and physical examination. Thyroid nodules have been found in 205 children, who were referred to IEM for additional evaluation. FNA was performed on 128 of this group, and papillary thyroid cancer was diagnosed in 20 patients. The diagnosis was confirmed by findings at surgery.

The epidemiological and clinical features of thyroid cancer were studied in 472 patients in Belarus who were less than 21 years old at diagnosis (Pacini et al., *J Clin Endocrinol Metab* 1997;82:3563-9). Differentiated thyroid carcinoma represented 98 percent of all thyroid carcinomas diagnosed in Belarus between May 1986 and December 1995. The results were compared with those of 369 subjects of the same age group, with naturally occurring thyroid carcinoma, observed in Italy and France. Between 1986 and 1989, the number of thyroid cancer cases per year ranged from 3–8 and increased to 31 in 1990, to 66 in 1991, to 72 in 1992, to 93 in 1993, to 96 in 1994, and to 90 in 1995.

The age at diagnosis was 14 years or less in 79 percent (children's group) and more than 14 years but less than 21 years in the remaining subjects (adolescents group). Mean age at the time of the accident was 4.4 years, the majority of the patients being 5 years old or less. Since 1993, the yearly distribution of new cases showed a decrease in the subjects 9 years old or more at the time of the accident but not in those 5 years old or younger. This could not be accounted for by a shift of exposed subjects to an age group at diagnosis not included in this study, because only subjects less than 12 years of age at the time of the accident were considered in this analysis. The female-to-male ratio was significantly higher in Italy and France (2.5/1), compared with the ratio of patients from Belarus (1.6/1). Extrathyroidal extension and lymph node metastases were more frequent in Belarus. The analysis of Belarus thyroid cancer patients less than 21 years old showed that the post-Chernobyl increase in thyroid carcinomas involved both children and, to a much lesser extent, adolescents. Subjects 5 years old or younger at the time of the accident accounted for the majority of the patients. No evidence of a decrease in the number of new cases was observed in this age group, as opposed to older subjects. These data support the concept that subjects who were younger at the time of radiation exposure had, and continue to have, a greater risk of developing thyroid carcinoma and strongly suggest that this age group should be carefully monitored in the future. When compared with naturally occurring thyroid carcinoma of the same age group observed in Italy and France, the post-Chernobyl Belarus thyroid carcinomas affected younger subjects, were less influenced by gender, were virtually always papillary, and had a greater aggressiveness at presentation.

These findings in Belarus are very pertinent to the screening for thyroid cancer in Ukraine because the northern raions of Ukraine adjoin the areas of exposure in Belarus.

B. THYROID CANCER SCREENING UNDER THE EXISTING SYSTEM

The Pre-existing System of Screening by Palpation

A pre-existing and ongoing system of thyroid screening in Ukraine appears to be functioning in at least some oblasts. For years, as part of an annual physical examination of children mandated by law, all oblasts have conducted screening of thyroid glands through palpation to find goiter and thyroid enlargement. This is part of a broader program of screening schoolchildren for various conditions. Thyroid palpation is performed by an experienced health care professional, such as a pediatric endocrinologist, at least in the northern raions of maximum radiation exposure in 1986. A public health program was initiated to promote the use of iodized salt in these areas, but the program is limited and goiter due to thyroid deficiency is common.

The oblast uses an outreach system similar to that of CCIP: it sends word in advance to schools and summer camps that children will be checked by palpation for goiter, after which a team comes through and performs this check. Thyroid palpation screening also finds other thyroid abnormalities, including thyroid cancer. In fact, 4 thyroid cancers in children have been found to date by this method in Volyn, 5–8 thyroid cancers in Zhytomyr, and 10 in Rivne. The Volyn cancers were discovered in 1995–96 in four children aged 12 or 13.

As shown worldwide, ultrasonography is a superior method of screening for thyroid cancer. Yet palpation screening appears to have found most of the thyroid cancers that have been discovered in children to date in the four CCIP oblasts. Therefore, this ongoing system has public health value and should be kept in mind during discussion about sustainability of project goals and objectives. This system appears to operate without foreign donor support, although it seems to have broken down in some areas, including in one oblast of CCIP implementation.

The Advantage of Ultrasound Screening

It is widely accepted that screening for thyroid cancer by ultrasonography is more sensitive than screening by palpation. Ultrasonography can detect nodules as small as 2 mm, whereas the nodules found by palpation generally must be 2 cm or larger. Solitary nodules larger than 1 cm are suspicious for cancer. The purpose of the ultrasound screening is to find nodules that are small cancers that can be treated more effectively because they will not have spread beyond the thyroid or into lymph nodes. In such patients, therapy is more likely to achieve a long-term cure.

Wiest et al. performed a study that is relevant to the comparison of palpation and ultrasound for detecting thyroid nodules in a group subject to radiation from the Chernobyl disaster (J Ultrasound Med 1998;17:487-96). Detection of thyroid nodules by physical examination and high-resolution ultrasonography was compared in a study of

113 Chernobyl nuclear reactor clean-up workers from Estonia. Positive high-resolution ultrasonographic findings were considerably more reproducible among different observers than were positive physical examination findings by experienced physicians. Agreement between methods was poor. Nodules were found in 169 (6.9 percent) subjects by physical examination and in 249 (10.2 percent) subjects by high-resolution ultrasonography. Physical examination found only 53 (21 percent) of the 249 nodules found by high-resolution ultrasonography. High-resolution ultrasonography did not confirm the existence of 115 (68 percent) of the 169 nodules found by physical examination. Only 6.4 percent of nodules less than 0.5 cm in diameter, as based on high-resolution ultrasonographic results, were detected by physical examination. Physical examination detection improved with increasing nodule size but was still only 48.2 percent for nodules larger than 2 cm. Physical examination was relatively effective in detecting nodules in the middle of the thyroid gland but much less so for nodules in the upper pole of the gland. The report concluded that epidemiologic studies of nodular thyroid disease stand to benefit from the greater sensitivity and specificity of ultrasonographic examinations.

These findings in Belarus are very pertinent to the screening for thyroid cancer in Ukraine because the northern raions of Ukraine adjoin the areas of exposure in Belarus.

C. GOALS, OBJECTIVES, AND PARTNERS

The goal of the CCIP is to develop a technically sound, high-quality, sustainable program for detecting and managing thyroid cancer.

The objectives of the CCIP are

1. development of a screening program,
2. carrying out the screening,
3. referral for management,
4. establishment of the diagnosis,
5. implementation of therapy,
6. maintenance of records of screening and management, and
7. sustaining the program after the support of CCIP funding ends.

The partners of the program include the following members:

- MSCI, the prime grantee and principal U.S. partner responsible for the technical and administrative direction and coordination of CCIP;
- Counterpart International, Drew University, Fordham University, Children's Hospital of Pittsburgh, Children's Hospital of Philadelphia, and Overseas Strategic Consulting Ltd.;
- the Ministry of Health; and

- oblast health services of the four oblasts: Volyn, Rivne, Zhytomyr, and Cherkassy.

The implementing organizations are four Ukrainian–American Health Centers (UAHCs) and their directors and staffs.

D. ACCOMPLISHMENTS IN EACH UAHC

Volyn

The program is based at the oblast pediatric hospital. The Volyn UAHC has screened 6,000 children and found 180 nodules that vary in size from 2 mm–2 cm. One ultrasonographer estimates that 25 percent are multinodular, usually small nodules; 75 percent are uninodular. He estimates that 50 percent of the solitary nodules are >1 cm. One to 2 percent show thyroiditis. The incidence of thyroid enlargement (hyperplasia) in various areas is 40–70 percent. This diagnosis is based on age and sex-adjusted size in cc estimated by ultrasound.

A pediatric endocrinologist on the staff has evaluated a small number of patients, perhaps 30. Patients over age 15 are referred to the endocrinologist at the adult oblast hospital. The evaluation includes tests of thyroid function. Currently, the CCIP manual requires measurement of serum thyroid stimulating hormone (TSH) to assess thyroid function, anti-TPO antibody and antithyroglobulin antibody to test for thyroid autoimmunity, and serum thyroglobulin. Reagents for these tests are not readily available and are probably expensive.

Nodules >1 cm should be biopsied; as a result, many biopsies must be done: $.75 \times 180 \times .5 = 68$. One probable cancer by ultrasound examination was found 1 week before the screening CCIP program started and was referred to IEM. An operation has not yet been performed on it.

The Volyn UAHC plans to screen the remaining 14,000 children and believes this can be done in 1 year. At the current rate of 700 per month (about 30 per day), it would take 20 months; if doubled to 60 per day, screening could be accomplished in half that time, allowing for completion in 10 months.

Table 1. Accomplishments of the Screening Program as of September 18, 2000

	Volyn	Rivne	Zhytomyr	Cherkassy
Inception of screening	9/15/99	10/11/00	4/11/00	1/31/00
Number screened	6,000	6,200	3,920	3,767
Target number	20,000	54,000	7,500	13,000
Percent of target	30	12	52	29
Number referred for abnormality	N/A	285	482	35
Number seen by endocrinologist	30	90	27	15 to oblast endocrinologist
Number with nodules	180	200*	78	100**
Number biopsied	5	0	0	0
Cancers detected	0	1	0	0

* estimated

** 35 solitary; 65 cystic or multinodular

Rivne

The UAHC, located in the Rivne Oblast Children's Hospital, is under the direction of an anesthesiologist. It took 3 months to assemble the equipment for the program. Screening started on October 11, 1999, and 6,200 children have been screened to date. The Rivne UAHC currently screens 60 children per day using one ultrasonographer and three psychologists, and completes about 300 screenings in one visit to a village school lasting about 1 week. Four ultrasonographers work in the program on a part-time basis; none are full time with UAHC.

The screening detected one papillary thyroid cancer. This was a 22 x 16 mm nodule in a child born November 22, 1985. The patient was operated on at the Ukrainian Institute of Endocrine Surgery in Kyiv (not IEM) and found to have lymph node involvement. He is followed by the oblast pediatric endocrinologist.

The range of abnormal ultrasound scans is about 6 percent and varies from 0–20 percent. Ninety patients have been referred to the pediatric endocrinologist. A review of the data on about 30 patients showed that 1 nodule 20 mm in size is regarded as suspicious for cancer, and that 6 more children have significant nodules. Two ultrasonographers at the diagnostic hospital are trained and experienced in FNA, making this technique available in the oblast for diagnosis of thyroid cancer. The oblast center has performed 20 FNA in children, but none of the children were from the raions involved with CCIP. This is because a decision was made to refer all CCIP children to the IEM in Kyiv for biopsy.

As part of the evaluation by the pediatric endocrine clinic, the ultrasound is repeated. About one fourth of the time, the small nodules that measure only a few mm in size are not confirmed on the repeat ultrasound scan.

Because of the large number of affected children in this oblast, screening at the current rate of 300 per week would require 159 weeks to complete the screening in this oblast.

The ultrasonographer, on site where the team visited, estimated that 3–4 percent of the children have thyroid nodules, and that a typical nodule is 1–1.5 cm. Diffuse hyperplasia related to iodine deficiency is common. Hyperplasia of a minimal degree is not referred to an endocrinologist, but larger hyperplasia is the most common abnormality and is referred.

Referral patterns show that patients may go to the raion endocrinologist, the oblast pediatric endocrinologist, the oblast adult endocrinologist, or the IEM in Kyiv. This makes it difficult to accumulate follow-up data. The oblast pediatric endocrinologist will now evaluate all referred children, including those up to age 18.

The six raions are in a region of endemic goiter due to iodine deficiency. Iodized salt is available in stores, but costs about 20 percent more than non-iodized salt. Iodized salt is used in the schools, but was not in stock in the school cafeteria visited by the team.

All school children in Rivne are supposed to be examined annually by a pediatric endocrinologist as part of the goiter screening program, which is part of a more comprehensive annual physical examination given to children in their schools. In recent years, the system of annual physical examinations seems to have broken down in Rivne. Nevertheless, these screenings apparently have detected 10 thyroid cancers in children before CCIP. The children underwent thyroid surgery in Kyiv at the IEM and they are now followed by the oblast pediatric endocrinologist.

Rivne is unique among CCIP oblasts because a Red Cross mobile thyroid ultrasound team also screens the population. It screens people of all ages and generally operates outside the oblasts of the CCIP.

Zhytomyr

The Zhytomyr program is directed by a pediatrician and is based in the sanatorium she heads. Approximately 7,500 Chernobyl children reside in the oblast in three raions. Screening started on April 11, 2000. The thyroid ultrasonography is performed by a single ultrasonographer who works full time in the sanatorium. The trips to the field last 5–7 days. There is a plan to obtain the service of another ultrasonographer.

As of September 8, 2000, 3,920 children have been screened. The Zhytomyr program currently examines 30 children per day. At this rate, the plan is to complete the screening by May 1, 2001.

In Zhytomyr, 482 children (12.9 percent) have thyroid pathology and have been referred to an endocrinologist. Seventy-eight children have nodules. The ultrasonographer estimates that about one fifth of the 78 nodules exceed 1 cm in size. Seventy-five percent of the thyroid abnormalities are hyperplasia, and about one third are of the third degree (significantly enlarged).

Data on only 27 children are available from the endocrinologist, who works part time at the sanatorium. Six of the 27 children had the diagnosis of thyroid nodule. Nearly all of the patients were treated with thyroxine. Although the oblast diagnostic center has several ultrasonographers who are trained in FNA, apparently none of the children with nodules have had this procedure yet.

Zhytomir is in an endemic goiter region. Approximately five to eight thyroid cancers in children were detected by the annual palpation screening program for goiter. The referral pattern and care of these patients is unclear.

Cherkassy

The program began in September 1999, and screening in the field started January 31, 2000. The UAHC is based at a pediatric sanatorium and is directed by a pediatrician. Currently the team includes one ultrasonographer and three psychologists. Screening is performed in six raions where the Chernobyl children reside. To date, 3,767 children have been screened by ultrasound, and 183 abnormalities have been identified. As of September 4, 2000, the rate of screening has been increased to 60 per day. Because the distance to the villages is relatively short, the team goes out for 4–6 days at a time. The recorder and printer have just been received, so no images have been printed or recorded. Because of this, the team plans to repeat the scans of children with abnormalities. Given the target to screen 13,000 children, another 9,233 children remain to be scanned. The program plans to complete the scans by May 1, 2001. At the rate of 1,400 scans per month, the additional scans to achieve the target number can be completed in 7 months, and this can be done before May 1, 2001. The problem of irregular power for electricity has been overcome by the purchase of a portable generator.

Of the 183 abnormalities found, 35 have been solitary nodules larger than 1 cm, 65 have been cystic lesions, and 83 have been diffuse enlargement of the second or third degree. The 35 children with nodules have been referred to the raion endocrinologist and are under surveillance in this way. The 15 children (of the 35) with nodules that are more suspicious for cancer have been sent to the oblast endocrinologist for further testing. The results of the tests have not been communicated to the UAHC. In the oblast medical facilities of Cherkassy, no one currently performs fine needle aspiration biopsies of the thyroid nodules under ultrasound guidance, so the children must be referred to Kyiv to the IEM for this procedure. A special probe for ultrasound-guided FNA is needed.

Ten beds in the pediatric sanatorium have recently been allocated for evaluation of the thyroid cases. However, their efficacy for detection of thyroid cancer is questionable because of the lack of facilities in the oblast for FNA.

Endemic goiter has been found in only two villages in Cherkassy and these are not in the six raions studied by UAHC. Nevertheless, all school children are examined for goiter by palpation by the raion pediatric endocrinologists annually, and this program has been carried out for at least 20 years. It is believed that the previous cases of thyroid cancer in children in Cherkassy have been detected by these examinations, but the number of children with thyroid cancer in Cherkassy is not known to UAHC.

E. CONCLUSIONS

Proportion of Target Screened

The proportion of the target population screened varies from 12 percent in Rivne to 52 percent in Zhytomyr. Although Rivne has 54 percent of the target population, this oblast operates with essentially the same resources for screening as the other UAHCs. While it is likely that three of the four UAHCs will reach the goal of screening all Chernobyl children in most contaminated districts in their oblasts, where other related programs do not work, this cannot be accomplished in Rivne without additional resources and more time for screening.

The plan now in place in three of the UAHCs to screen 60 children per day means each screening is performed in less than the 20 minutes mandated for each thyroid ultrasound. Reducing the time per ultrasound so that 6–10 per hour may be performed is justified because the main goal of screening is detection of solid nodules. Furthermore, children of this age group are easier to examine than older adults. The downloading of the data into the computer after the screening, as practiced in Rivne, saves time and should be adopted by each UAHC to improve efficiency. One obstacle to the screening has been the occasional lack of electricity. This has been overcome by bringing a mobile generator to the school.

As noted earlier, half of the projected screening was not completed before the midterm evaluation. This is due in part to delays in procurement of equipment. The annual screening goal prescribed in the CCIP procedures manual for Chernobyl children is clearly unrealistic.

Detection of Thyroid Nodules

The screening program has detected thyroid nodules in about 2–3 percent of Chernobyl children. This is a large number of nodules in an adolescent population. Additional follow up of these children is required. The large proportion of endemic goiter (hyperplasia) in three of the four oblasts is a confounding problem. The hyperplasia probably predisposes to the development of small nodules, and they may be more difficult to detect technically in a hyperplastic gland. Nevertheless, in a population predisposed to thyroid cancer, these thyroid nodules require additional evaluation by referral to an endocrinologist.

Referral Patterns

Because the goal of screening is detection and therapy of thyroid cancer in an early phase, referral of the patients with abnormalities to an endocrinologist is essential. The current referral plans of the various UAHCs have some common features but are not uniform. For each child with an abnormality, a referral form is prepared. If the abnormality is minimal hyperplasia, the form is sent to the raion endocrinologist. If the abnormality is more severe, the form is sent to the oblast endocrinologist. These abnormalities include thyroid nodules, higher degrees of hyperplasia, and thyroiditis. The patients of interest to the goals of CCIP are those with thyroid nodules.

In general, the oblast pediatric endocrinologist will repeat the ultrasound study, make a diagnosis, and initiate therapy. Data on the various diagnoses, management, and treatment were generally not available. The reasons for this lack of data on follow up are the following:

- Although children are referred, often they cannot go to the doctor because of problems with transportation or lack of funds for family to accompany them.
- Parents choose to ignore the problem.
- The program design seems not to have mandated a requirement for the UAHC to maintain a record of the follow-up management in regard to diagnosis and therapy; it mandated only that a referral be made.

Implementation of a travel voucher system from the Ministry of Emergencies would help to overcome the problem of transportation.

To improve the retrieval of records of management of referred patients, it would be preferable to add the oblast pediatric endocrinologist to the UAHC as a full member of the team. This may also improve follow up of patients and help facilitate having the patients see the pediatric endocrinologist. The current liaison in this respect is inadequate.

Referral Evaluation by Oblast Endocrinologist

The blood tests required by the CCIP manual for evaluation of nodules >1 cm are inappropriate. Serum TSH measurement is appropriate to evaluate thyroid function. It is reasonable to conduct one test (serum anti-TPO antibody) for autoimmune thyroiditis as the cause of the nodule, but not the additional test of antithyroglobulin antibody because it would yield at most another 20 percent of cases of thyroiditis. The measurement of serum thyroglobulin for evaluation of the nodule is entirely unnecessary, and this is a difficult and expensive measurement. This test should be eliminated.

Fine Needle Aspiration Biopsy (FNA)

The recognized test for diagnosis of thyroid cancer related to radiation is FNA. Thyroid ultrasound is a screening procedure to select patients for FNA. In the case of solitary

nodules larger than 1 cm (and usually not palpable), the FNA must be performed under ultrasound guidance. This requires a small ultrasound probe, training of the ultrasonographer (or endocrinologist) in FNA under ultrasound guidance, and a cytopathologist with experience in reading the slides obtained by FNAs. It was claimed that such expertise was available in Volyn where five FNA were performed. In Rivne, the decision was made to refer all biopsies in children to IEM in Kyiv. This technique is not available in Zhytomyr or Cherkassy. Because of lack of availability locally and the difficulty of going to Kyiv, the procedure has been seriously underutilized to date.

The IEM has the best recognized expertise for thyroid FNA and is the institution where surgery is to be performed on children with FNA indicative of thyroid cancer. An IEM representative stated that it may be possible to send a doctor from IEM who is experienced in ultrasound-guided FNA to perform the FNA in the oblast hospital if 5–10 children can be assembled for the procedure and if suitable financial support can be arranged to defer the cost of travel and supplies. An additional advantage of such an arrangement is that the IEM would become a more active partner in the CCIP, as envisioned in CCIP design, and as may be necessary to have lasting impact on Ukrainian policies and procedures regarding thyroid cancer management.

To overcome the problem of transportation to the oblast center or IEM for evaluation and FNA, funds to pay for the transportation should be provided when no other option is available.

More importantly, CCIP should provide training so that at least one health facility in each of the four oblasts has someone able to perform ultrasound-guided FNA biopsy. This would solve the problem of transporting children to the IEM in Kyiv. It would also build important capacity at the oblast level.

Efficacy of CCIP for Detecting Thyroid Cancer

With the screening of 20,000 children to date, the program has detected one thyroid cancer, yielding an incidence of 20 cases per million per year. This is approximately twentyfold the incidence of a nonirradiated population.

Based on the screening of the sample of 20 percent of the targeted population, a conservative estimate is that about 1 percent will have significant thyroid nodules. It is likely that needle biopsy will detect about 6 percent of the thyroid nodules as definite thyroid cancer or suspicious for thyroid cancer, and indicate that surgery should be performed. Therefore, the expected number of thyroid cancers is: $.01 \times .06 \times 100,000 = 60$.

Another approximation of the expected number of thyroid cancers may be deduced from the experience of the NCI-IEM ongoing study. In a group of 11,000 children who have been screened, 20 thyroid cancers have been found. This group includes individuals who were up to age 18 in April 1986, so most of them would not be in the most vulnerable age group (age 0–6). However, it is possible that the radiation burden was greater in the NCI-

IEM patients; these factors may balance out. Nevertheless, the number of cancers expected using these data for estimation would be 36.

It is likely that the reason for not finding these cases is a lack of follow up and a lack of utilization of FNA in children with solitary thyroid nodules.

The IEM declined collaboration with CCIP for various reasons, one being an impasse over program compensation for IEM staff participation.

Reaching the Target

To attain the target of screening 100,000 children, it will be necessary to greatly increase the number screened in Rivne. Accomplishing this will require the addition of at least one more team so that the number screened can be increased to 600 per week. In addition, it will be necessary to add one more year (a fourth year) to the current program in Rivne. Without these changes, most of these children will leave school at age 17 or 18 without having been screened.

Continuation of the Screening

It may be feasible to continue the current program of screening without additional funds beyond a four-year period. This would allow a second ultrasound screen. Ideally, these vulnerable populations should be screened at regular intervals. How often ultrasound screening should be performed is unknown. Intervals recommended by the staff who were interviewed, the original design, and other sources vary from once every 6 months to once every 3 years. Screening every 3 years seems to be a reasonable interval for individuals with no nodules but who are in this high-risk group.

Comparison with Palpation Screening

Before the CCIP, the cases of thyroid cancer were discovered by the palpation screening of school children on an annual basis. Although this program is mandated by the MOH, it has not been carried out regularly in recent years. Even though it lacks the sensitivity of ultrasound, it is relatively low cost and should be continued in the affected raions. Such screening is far better than no program at all.

Treatment of Endemic Goiter

The treatment of endemic goiter is a serious problem for three oblasts. Provision of iodized salt in the schools is essential. Continued publicity about this problem is important. As noted above, the frequency of hyperplasia is high, accounting for about three fourths of the abnormal thyroid ultrasound scans. It also confounds the screening program. More effective prevention by public health authorities is needed.

F. RECOMMENDATIONS FOR IMPROVEMENT

- The CCIP program has accomplished a great deal and is very important to Ukraine for follow up of Chernobyl children. Although it was delayed in getting started for a variety of valid reasons, it has screened more than 20,000 children to date. The program should be continued and given a no-cost extension for a fourth year to complete the screening of each child in the targeted population. In addition, the program should be extended beyond the fourth year until the current funding is exhausted or for three more years until all the children are 18 years old.
- Because it contains more than half the children targeted for screening, Rivne screens a low proportion of children compared with the other programs. The Rivne UAHC should be given additional resources consisting of equipment and personnel to make up a second team so that two teams can be in the field simultaneously.
- Each UAHC should incorporate a pediatric or adult endocrinologist into the funded team to improve the follow up of referred children.
- Children with nodules of 1 cm or larger should be followed with annual ultrasound examinations and FNA as appropriate. Follow up with FNA is essential for making early diagnosis of thyroid cancer. The UAHC must be accountable for the follow up and treatment of each child with a thyroid nodule of 1 cm or larger.
- Each UAHC should be held accountable for obtaining follow-up information on all of the children with nodules of 1 cm or larger.
- Training should be provided so that each oblast will have the capacity to perform ultrasound-guided FNA biopsy in at least at one health institution in each of the four oblasts of CCIP assistance. The IEM ought to be able to provide such training.

G. IODIZED SALT IN SCHOOL CAFETERIAS

CCIP staff have discussed the thyroid deficiency problems resulting from lack of iodine in the diet in the northern raions of the CCIP oblasts (except Cherkassy) and the public health value of finding ways to address this problem, the extent of which was not known during the program design stage.

There was more iodized salt in the diet during the Soviet period than at present. Reasons for its lack today are that iodized salt costs about 20 percent more than regular salt, and that people simply do not like it. Moreover, even if found and consumed, the iodine content may be distributed variably so that goiter is not prevented reliably.

Recommendation

Iodized salt should be purchased by the project (local cost is 10 cents per kg) and delivered by the mobile teams to schools during screening visits. This source of iodine can be added to consumables in the school cafeteria. Having some iodine in one meal a day (possibly an important meal for children from poor families) is far better than no iodine at all and might go some way toward mitigating thyroid deficiency conditions.

V. THE PSYCHOSOCIAL COMPONENT

A. BACKGROUND AND RATIONALE

U.S. government concern over the consequences of the 1986 Chernobyl nuclear disaster led the U.S. Congress to authorize \$5 million for “the screening and treatment of physical and mental illness” due to the catastrophe. There was much evidence of the psychosocial impact on children and families from the literature and anecdotal reports. In addition, it is well known that similar environmental catastrophes have produced symptoms of posttraumatic disorder, especially in children who are most vulnerable, and that medical disorders in children are accompanied by psychosocial and behavioral problems.

Although it is difficult to scientifically attribute increases in depression, anxiety, and behavioral problems directly to the impact of this event due to many other factors—for example, the economic condition of this nation in transition, long-term effects of many years of poverty, and displacement of communities and families following the accident—there are many reports of increased symptomatology in the child and adolescent population. A study conducted in Ukraine found that prior to the Chernobyl disaster, adolescents estimated their life span to be about 90 years; after Chernobyl, this was reduced to 60 years. The same adolescents saw the event as a critical part of their lives, even if it occurred prior to their birth. Families attributed their declining health to Chernobyl, and pregnant women expressed fears of delivery in other reports. Given the evidence cited above, it is important to counter statements from some quarters belittling the psychosocial consequences of Chernobyl as “indirect” and recognize them instead as important as the effects of radiation.

The Chornobyl Childhood Illness Program

A unique aspect of the CCIP is its mandate for the evaluation and treatment of psychosocial problems in addition to thyroid cancer screening. USAID involvement in funding programs dealing with psychological problems is relatively new and this program provides a possible pilot model for future support in this crucial area.

Mental Health Services in Ukraine: A System in Transition

Ukraine lacks an organized system for the delivery of psychological services. Indeed, clinical psychology has only recently emerged as a profession in the country. Typically, psychologists have worked in schools or in industry and have primarily been involved in assessment and diagnosis of learning disorders, mental retardation, or aptitude. The notion of providing psychotherapeutic services is new, especially providing services in the community rather than in hospitals and other large institutions. Thus, the program design included an intensive training component of professional psychologists; indigenous nonprofessionals and nonprofessionals in the communities served, such as

nurses, teachers, administrators; and youth social service workers. Psychologists were assigned to the mobile screening teams from the outset to evaluate children using the Children's Depression Inventory (CDI) and other observations and to individually interview children. Their objectives were to screen for high-risk children, provide crisis intervention, and refer children for further service. Training was provided by faculty at Fordham University, Drew University, and Children's Hospital in Philadelphia.

Objectives of the Evaluation

As designated in the scope of work, the psychologist evaluator was to perform a midterm evaluation (the program is well into its third year) of the psychosocial component of the program. This included identifying, quantifying, and documenting outputs and results to date of the CCIP; assessing its impact on other institutions and systems as well as on beneficiaries; evaluating the benefits in terms of costs, potential for systemic change, and potential for sustainability; identifying constraints to successful completion as well as successes; and recommending effective strategies and changes for the future of the program.

B. MAJOR FINDINGS AND ACCOMPLISHMENTS

Oblast Programs

There were numerous delays in starting up the program due to the creation of initial memoranda of agreement, equipment problems, finding and hiring the teams, and training, to name a few. The first screenings were conducted in Volyn Oblast in August 1999. Rivne began in September 1999, Zhytomyr in May 2000, and Cherkassy in January 1999.

- In **Volyn**, 6,007 children have been screened. Currently there are two psychologists, with plans to add a third. Eight hundred and sixty (860) children have been referred for further evaluation and treatment (14 percent). About 33 percent follow through with referral. The target number of children is 20,000. The director was highly supportive of psychosocial programs. There has been an attempt to set up a nongovernmental organization (NGO) for sustainability. The psychologists were very concerned about the future of the children they have seen.
- In **Rivne**, the three psychologists have screened 6,500 children out of a target number of 54,000. Rates of identification of depressed children from the CDI range from 15–33 percent in the different raions, with an average of about 20 percent. Here, psychologists were interviewed and observed in the field in a rural school. Part of their task has been to educate children, school staff, and the public about the role of psychologists. They give a general talk in all classrooms and look for especially sensitive teachers who may be able to follow children with psychological problems. This is the raion with the largest number of targeted children and the largest number still to be screened.

- In **Zhytomyr**, 3,920 out of a target group of 7,500 children have been examined. With a current rate of about 50 per day, the expectation is completion by the three psychologists by May 2001. Four hundred and two (10.25 percent) have been identified and referred in one raion. The expectation is for higher rates in the other two, which are poorer and have higher rates of alcoholism and other psychosocial problems. The director was highly supportive of the psychologists. All referrals are given to the raion pediatrician for referral. There were no data available on the rate of follow through.
- In **Cherkassy**, 3,700 children out of a target number of 13,000 have been screened. The UAHC director was highly supportive of the psychosocial project. Four additional raions are to be screened. Sixty children a day are being screened. Six hundred and forty-four children with high scores have been identified (17.4 percent). The psychologists are making good use of community-based services for referral, including school psychologists (when available), social service workers, teachers, and other caregivers. They said referrals to oblast centers are rare and there were no data on follow through.

Recommendations

- The team recommends the continuation of the psychosocial program and a no-cost extension for a fourth year to the oblasts most in need. In addition, due to the large number of beneficiaries in Rivne that need to be screened, resources should be reallocated from Zhytomyr to Rivne after Zhytomyr completes screening. Another option would be to allocate new resources to Rivne.
- The current incentive system, by providing rewards for seeing more than 60 children, may emphasize quantity over quality. One approach would be to cap the maximum fee per diem awarded for seeing more than 50 children. In this way, psychologists would be encouraged to spend the maximum time possible with a child without sacrificing their per diem fees.

C. GENERAL OBSERVATIONS

There is a high level of enthusiasm for the psychosocial program in all four oblasts as reported by psychologists, children, and administrators. The psychologists also expressed great compassion for the children; indeed, the psychologists have been very well received in rural raions, where the notion of psychological services had been unknown. This has been demonstrated in the self-referral of children with a broad range of psychosocial problems including depression, anxiety, posttraumatic stress, physical and sexual abuse, family alcoholism, etc. The addition of a third psychologist on the mobile teams has also improved the efficiency of screening and crisis intervention. Initially, only one psychologist was available on each mobile team. It was discovered that the psychologists needed more time than the physician screeners because they also did crisis intervention. After a second psychologist was added, the teams decided that a third was ideal. All team

psychologists now believe that this is an ideal number for handling 50–60 children per day.

An important psychological finding is the reported relief of parents when they learn that their children do not have cancer. The significance of this cannot be minimized given the high level of fear about cancer in this population.

All the psychologists demonstrated a high level of professional competence. This was manifested in their discussions with the team as well as in case presentations that involved creative, strategic interventions at the individual, family, and community level. For a poor nation in transition, the role of psychologists in dealing with psychosocial problems is key as increasing evidence shows that transition most affects the psychological well-being of children. The experience of Ukraine through the CCIP program, in which USAID has recognized the importance of psychosocial issues in development, will have great relevance for other development programs. A well-developed and well-trained profession of psychology will continue to be beneficial for Ukraine, where high rates of alcoholism and other family-related problems are also present.

Recommendations

A concerted effort should be made to continue the advancement of the new profession of clinical psychology in Ukraine. This includes support for such things as professional organization and lobbying, increased training opportunities, and peer supervision and consultation. The importance of this support for services for children cannot be overstated.

Case Examples

- In Volyn, a 17-year-old boy was isolated, severely depressed and discriminated against by other children because of his appearance. The intervention included pairing him with another boy with similar problems for support.
- Another teenage girl with severe depression and family problems, including loss of her father and distance from her mother, was treated with a unique combination of individual and family therapy to correct miscommunications and bring the girl and her mother back into a relationship.
- A 15-year-old girl was living with an alcoholic mother and stepfather who also abused her. Rather than sending her to an orphanage, the team found a “godmother” to take her in.
- In Cherkassy, a 13-year-old boy with aggressive behavioral problems and social isolation was found to have little trust after his father deserted him. Through a variety of creative interventions, the psychologist gained his trust and he became open to psychological counseling. These interventions combined individual, family, and community approaches which were emphasized in the training.

D. RELATIONSHIP OF CHERNOBYL TO MENTAL HEALTH PROBLEMS

The mobile team psychologists have been trained to identify mental health problems in addition to the depression manifested in high CDI scores. Administrators, physicians, and others interviewed in the field were also asked to comment on the relationship of the

Chernobyl disaster to the mental health problems in the raions. With one exception, in which an informant believed that radiation directly affects the brain and causes depression, most saw the relationship as indirect. Factors mentioned include the overall fear of long-term consequences, an increase of alcoholism in the affected communities (including the fact that Soviet authorities distributed vodka to victims), the effects of family and community displacement (a number of the rural raions have large numbers of families or whole villages that were moved), the long-term effects of poverty and malnutrition, and isolation and lack of resources for children and adolescents in general.

E. TRAINING

The training provided in the area of mental health has been very effective for both professionals and paraprofessionals in the community. There was unanimous positive feedback on all trainers from psychologists, school psychologists, teachers, administrators, youth service workers, Red Cross nurses, and UNESCO social workers and psychologists. They were especially pleased with practical training techniques, which included role playing and other experiential techniques. More than 450 (out of 250 planned) individuals have participated in training sessions, compared with a maximum of 16 psychologists in the total program. All trainees reported that they wanted additional training in practical therapeutic techniques.

Recommendations

The psychosocial training provided in this component has been highly effective, having provided psychosocial aid-related workers with a foundation of knowledge and skills. Future training should focus on further strengthening this network of providers by offering more advanced refresher courses for each aid category. The spread effect of training school psychologists, nurses, youth service workers, and others will greatly enhance the sustainability of the program. These individuals are in the best position to provide ongoing services to children in rural regions. For example, Red Cross nurses who make home visits could develop basic counseling skills to help families, teachers, and school psychologists identify and work with troubled children. Training should focus on individuals and groups that have the most contact with children in need in these rural communities, and who have proved their interest in providing such services. One trainer, a clinical psychologist, was most frequently mentioned as being helpful to trainers. As developing professionals, the psychologists believed that a psychologist with clinical training who could help them with actual case material was the most effective type of trainer. This information should be used in planning future training sessions.

Spread Effects and Recommendations

Among the many benefits and results of the program has been that a broad group of individuals outside the original scope of the program have been trained in psychological skills. The increased confidence of these community-based workers in identifying and counseling children is likely to enhance program sustainability. These workers will probably continue to see children after the program is completed. In addition, given the

problems faced by the referral system, community-based services have the best chance of reaching the most children.

The program has also resulted in enhancing the profession of psychology overall, not only for the psychologists but for the beneficiaries as well. Psychologists trained by CCIP now have counseling skills and are continuing with professional and peer supervision and training. The private practice of psychology has been legalized in Ukraine, which will benefit families and add to the employability of psychologists. Furthermore, there has been widespread exposure to psychological services and a public education benefit to populations that previously had no knowledge of such services. UNESCO's Chernobyl project (now run by UNDP) runs a community service center in Zhytomyr in a different raion than that served by CCIP. Nevertheless, the training received by workers at this center may aid youth in the region. In the United States and in poor countries, the community-based model has been found to be the most feasible for service development. In such countries, where resources are scarce and the notion of mental health is new and frequently stigmatizing, the use of community "gatekeepers" as resources for counseling children and families has been proven to be helpful. Therefore, the identification and training of such community resources as nurses, clergy, teachers, and social service workers is critical.

To further enhance the spread effects of the program, the following recommendations are suggested:

- Interaction between service providers such as psychologists, school psychologists, Red Cross nurses, and youth service workers needs to be increased and coordinated to improve continuity of services and to avoid duplication of services.
- Although costly, the decentralization of services out of central cities in the oblast raions will be most effective in the area of service delivery. This approach can be studied closely in community-based models. For example, one idea would be to use professional psychologists as consultants and referral sources for the community-based indigenous professional, such as Red Cross nurses, youth service workers, and school psychologists, who will continue to provide the bulk of the services. Service models such as crisis telephone lines and support groups such as Ala-Teen could also be considered.
- It is critical that psychosocial programs are able to be sustained at the program end. Efforts should continue to search for alternative funding sources for such programs from foundations and other nongovernmental sources.

F. PROBLEMS AND CONSTRAINTS

The problems in initiating the screenings for both thyroid and psychosocial screening have been documented earlier in this report. In addition, numerous problems plague the already complex and inefficient referral system for psychosocial follow up of children at

risk. In addition to the complexities in how children are referred—often different systems in the same oblast have little to do with clinical decisions—children and families do not follow through because of economic issues, large travel distances from rural areas, the stigma of mental illness in families and communities, and family dysfunction such as denial or fear of the consequences of abuse and alcoholism being discovered. As a result, most treatment is occurring at the community level with brief crisis intervention. Psychologists are concerned about what will happen to children in greatest need after their consultations and about those who need more intensive, long-term psychological treatment. Efforts are being made to improve referral systems and provide more effective services at central oblast levels, but whether this will improve follow through is unknown.

Recommendations

- Efforts must continue to improve the psychosocial referral system and to facilitate feedback to psychologists and administrators on the outcome of referrals. This feedback loop will facilitate more effective interventions. Secretaries in the UAHC centers are in the best position to obtain and compile this information.

Another problem is screening children who are absent from school or summer camp because they are at home helping their families. The incentive pay system has also hampered development of an effective referral system by encouraging quantity of screening over quality. The pressure to see even more than 60 children a day by the three psychologist teams appears to have interfered with the level of crisis intervention that was able to be provided, an important service given that many of these children do not follow through with referral.

Finally, there was evidence of occasional conflict on the teams between the psychologists, whose mission was to provide counseling services to children, and the physicians and drivers, whose mission was to screen as many children as possible. This conflict was fueled by the fact that the psychologists are dependent on the other team members for such services as transportation and scheduling.

VI. MANAGEMENT AND ADMINISTRATION

This section reviews the overall management and administration of the program, including the prime–subcontractor relationship as well as national- and oblast-level management issues.

A. OVERALL MANAGEMENT MODEL

The CCIP program director manages the program on a part-time basis and jointly with subcontractor consultants, from the United States. This arrangement provides a significant financial savings to the program. Instead of having a full-time expatriate program director in-country, in-country management is provided by a subcontractor, Counterpart International (CI), which employs a Ukrainian deputy director with general administrative and logistic responsibilities. Experience managing medical programs in close contact with the host-country health care system initially was not required, which, in the absence of the full-time in-country medical director, hampered timely implementation. The deputy director reports in part to the CI country director. There is also a full-time Ukrainian manager of the psychosocial program component, a psychologist. This individual works for the prime contractor, which does not have an office in Ukraine.

This management model is somewhat unusual for a USAID program of this scale. Although it seems to work and to have saved money for program implementation, it has added difficulties to program implementation, including a delayed startup. In the third year of a three-year, \$4 million program, about half of CCIP's total funds have been spent. This could be seen either as an achievement or a failure to implement on schedule. The team understands the reasons for the late startup of the mobile team screening system and prefers to regard the savings as an asset that could provide additional time (a fourth year, no-cost extension) to achieve CCIP objectives. It could also help address the complex issue of sustaining CCIP activities beyond the life of the project (see section VIII, Sustainability of CCIP Activities Beyond the Life of the Program).

The UAHCs participated in three technical and administrative conferences in which each mobile team presented its findings. These seminars also addressed administrative issues and plans for sustainability.

B. PRIME–SUBCONTRACTOR RELATIONSHIP

The relationship between the prime contractor, MSCI, and its subcontractors appears to be smooth, and no significant or ongoing problems were encountered. The prime contractor reported that the best possible relations have been developed between the implementation partners. MSCI and the subgrantee partners also meet every 6 months to

discuss project activities and progress. These meetings were said to be useful in addressing technical and administrative issues and problems that have occurred.

At first glance, seven subcontractors engaged for a \$4 million program might seem like an unusually large implementation team. The reason so many subcontractors were chosen is that the project's implementation strategy emphasized individual technical skills combined with regional experience, rather than institutions. Building a team based on optimal skills and experience tends to involve more institutions than a relatively small program utilizing a different approach.

In addition, some contractors, such as Overseas Consulting, had one-time or short-term assignments rather than a longer term subcontractual relationship with CCIP. In practice, Counterpart International has been responsible for most in-country administrative matters, Drew and Fordham Universities for most psychosocial training, and Children's Hospital of Pittsburgh (one endocrinologist) for thyroid cancer matters.

Although the team did not focus on management issues, there appear to have been problems related to lack of clear lines of authority. Occasionally difficulties would arise in areas such as cash flow, in this case related to one of the university subcontractors transferring funds to Ukraine for a training seminar. These problems appear to have been resolved.

C. NATIONAL LEVEL

The CCIP had planned to work with the Kyiv-based IEM as a national partner. However, this did not work out for various reasons. There may still be ways for the CCIP and the IEM to work together more closely. For example, if CCIP can find ways to use IEM endocrinologists in the field, this will increase the chance that CCIP can have a lasting impact on national policies and procedures related to thyroid cancer. Another way to increase involvement would be for IEM endocrinologists to train oblast endocrinologists to perform biopsies in the three oblasts where ultrasound-guided FNA capability is lacking.

D. OBLAST LEVEL

Management problems relating to communication between CCIP implementation partners were encountered at the oblast level. Depending on where a given UAHC is located, key local partners may be spread out at various institutions, such as sanatoriums, oblast health centers, and diagnostic centers. Some staff benefit from CCIP directly in the form of per diem. Others, such as child endocrinologists who are supposed to perform biopsies, do not. As a result, key players have different levels of motivation to work toward CCIP goals. Combined with physical dispersal of the UAHC team, this situation makes it difficult to hold regular meetings, or any meetings at all.

This problem will be difficult to resolve without interfering in the existing system of salaries, incentives, values, and expectations of oblast health professionals. For example, follow-up FNA biopsies of suspicious thyroid nodules are essential to finding thyroid

cancer. Because the full and active participation of the referral resource (e.g., a pediatric endocrinologist) is essential to achieving this, it would be useful to make the endocrinologist a formal member of the UAHC. This could be done by providing the endocrinologist with a monthly consulting honorarium or per diem. On the other hand, there have been reports that such compensation has produced problems and provoked jealousy from colleagues who are not benefiting in the same way. In one case, some psychologists on loan to UAHCs from oblast institutions were fired from their regular government jobs because their supervisors reasoned that the psychologists were now being taken care of by CCIP. Given this concern, it would be useful to also look into noncash incentives.

VII. PUBLIC AWARENESS CAMPAIGN

One CCIP objective is to make the general public more aware of the program, in particular of the value of screening, diagnosis, and treatment of thyroid cancer and depression. To this end, 1.2 million CCIP brochures have been printed and are being distributed. In addition, a videotape about the CCIP screening program has been completed and is also being distributed. Both public awareness materials were pretested in focus groups and were approved by USAID/Kyiv.

According to CCIP/Kyiv, the contribution of the U.S.-based subcontractor in pretesting and developing the public awareness brochure has not been timely or cost-effective. Therefore, CCIP should identify local expertise in marketing, advertising, and mass media (probably in Kyiv), and use this expertise on an as-needed consultant basis. Not a great deal of technical assistance in this area is anticipated, but some should be appropriate to disseminate messages via radio and television.

One mobile team psychologist trained by CCIP already has her own radio program in Cherkassy. On this live, call-in show, people with problems relevant to CCIP activities (e.g., depression, alcoholism, family abuse, drug addiction) telephone the show's moderator and ask the psychologist for advice. Advice may involve on-the-spot crisis intervention or referral to available resources in local areas. CCIP training has made this psychologist better at handling and referring people with such problems. This radio show is an excellent way to broadcast the messages of CCIP. CCIP should look into opportunities, including tying into existing discussion or call-in programs, in other oblasts for such programs.

VIII. SUSTAINABILITY OF CCIP ACTIVITIES BEYOND THE LIFE OF THE PROGRAM

Any consideration of sustainability should begin with asking what needs to be sustained. The broader effect of a “sustainability solution” on the government of Ukraine and on Ukraine in general should also be considered. The legacy of the CCIP should be to strengthen the capacity of Ukraine in managing thyroid cancer, specifically in the screening, diagnosis, and treatment of thyroid cancer, and in related psychosocial problems. This strengthening should be at the oblast health-department level, and it should focus on ensuring that adequate technical capacity can be found in oblast institutions that manage thyroid cancer and related psychosocial problems.

A USAID–assisted program should not interfere with or weaken existing government of Ukraine (GOU) services and systems. Nor should it detract from GOU responsibility in providing services.

From CCIP documents and discussions, three ideas emerge on ways to sustain program activities beyond the life of the program. A fourth suggestion has been added for consideration by the CCIP and USAID:

- Establishing a national-level NGO to help the four CCIP UAHCs continue their activities in the future. These would need to attract financial support from foreign and perhaps local donors, for future activities.
- Establishing four or more oblast-level NGOs for the same reason as stated in the previous point and with the same expectations. These might involve existing personnel from the four UAHCs and be attached to the oblast health institutions where the UAHCs now operate.
- Finding a way to support existing, established NGOs as a way to continue certain activities.
- Finding ways to build on the existing, ongoing GOU system of palpation screening that occurs, in least in some areas, when children are given annual physical examinations in schools.

In principle, it makes more sense to build on an existing system with similar activities than to create a new one from scratch. However, this idea needs further exploration. For one thing, the existing system would have to be a functioning one. The team was unable to determine empirically the extent to which annual physical examinations are carried out, as well as the quality of thyroid examinations in schools where these examinations are performed. This information is likely to show great regional variation. However,

where such physical examinations are taking place, there is something to build on, namely a government program that involves multidisciplinary teams visiting schools to do various types of screening. This includes, at least in Chernobyl-affected raions, thyroid screening by palpation. There may be a way to add ultrasound equipment to this procedure, as well as one or more psychologists trained under CCIP.

The vehicles purchased under the program will also be available at the four oblasts of CCIP implementation. If there is a will on the part of oblast health authorities, mobile teams could continue to visit schools to conduct the same screening and referral that occurs under the CCIP.

As for NGO-related options, these organizations could serve as pressure groups to push for actions in the public sector; they could also carry out some of these activities themselves. Regarding the latter, now that all UAHCs have equipment and staff, actual costs of conducting screening and referral are modest because there are no substantial salary costs at the oblast level. Estimates of direct costs for carrying on screening at the oblast level are approximately \$80,000–\$100,000 per year (for example, fuel and per diem, and not including managerial overhead at higher levels nor expatriate consultant costs).

If the program spends judiciously for the remainder of the life of the program, even assuming a fourth year, there should be funds left over that could serve as a bridge providing support to a new NGO to continue present program activities. For example, \$500,000 could keep activities going for five years. This would allow more than adequate time for the new NGO to attract additional funds. In fact, the 0-to-6-year cohort of children at risk for thyroid cancer as a result of the Chernobyl accident will have passed beyond school age in 2005, so the present program would no longer be needed five years from now, at least for thyroid screening. The psychosocial needs can be expected to continue for the foreseeable future.

ANNEXES

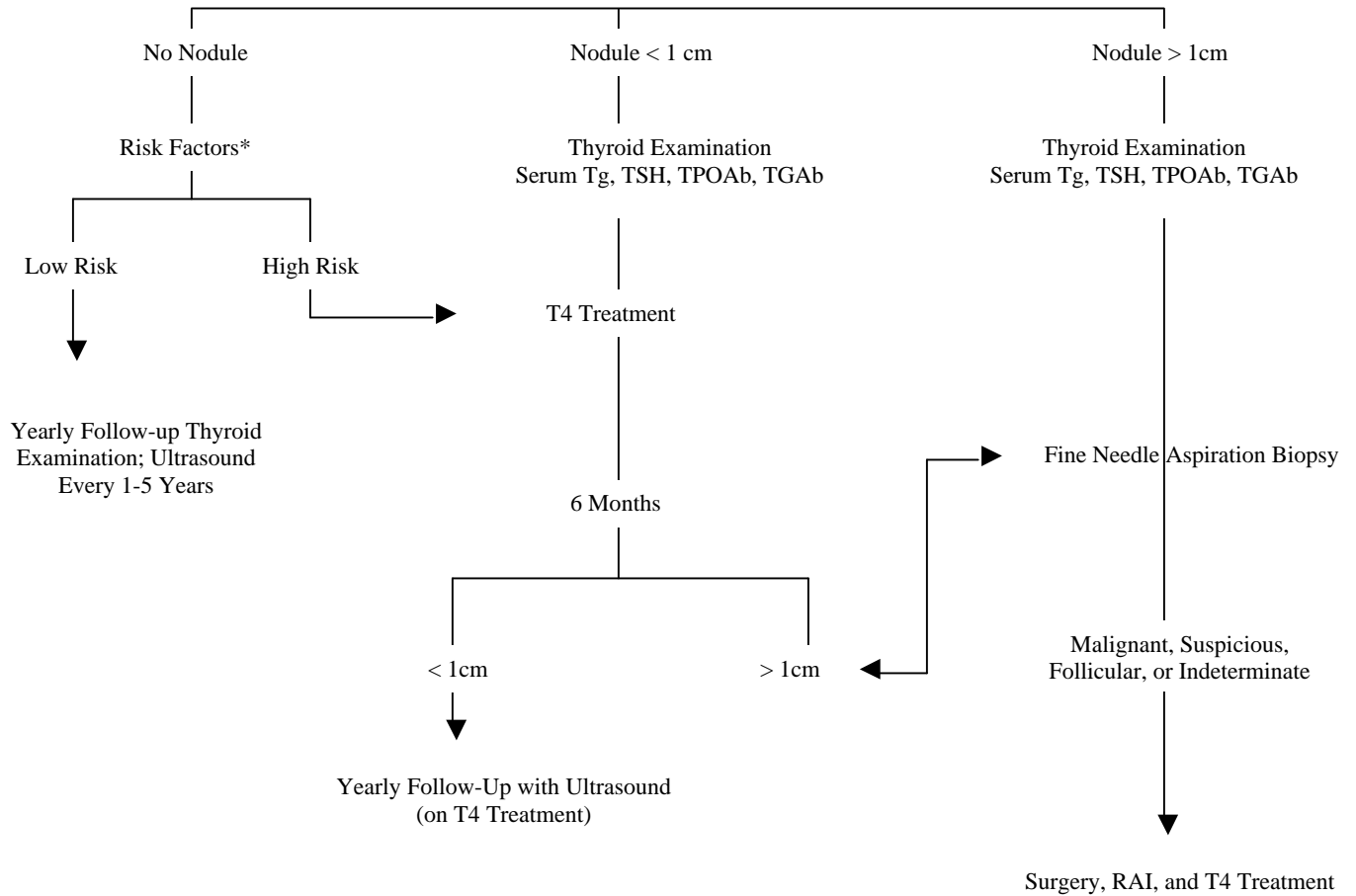
A. Clinical Evaluation Algorithm	45
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ANNEX A

CLINICAL EVALUATION ALGORITHM

Clinical Evaluation for Thyroid Neoplasia

Thyroid Ultrasonography Screening



*Risk Factors

1. Young age at radiation exposure
2. High-dose radiation exposure
3. Familial susceptibility
4. Elevated serum Tg concentration

ANNEX B
PERSONS CONTACTED

Persons Contacted

Medical Services Corporation International

Mr. George Contis	President and Project Manager
Mr. Richard Joseph	Project Assistant
Ms. Cynthia Turner	Vice President

USAID/Kyiv

Ms. Olena Radziyevska	Project Manager
Ms. Alexandria Panehal	Deputy Mission Director
Ms. Marilyn Schmidt	Director, Office of Democratic and Social Transition USAID/Kyiv
Ms. Pamela Mandel	Deputy Director, Office of Democratic and Social Transition
Dr. Borys Uspensky	Project Manager
Dr. Eliot Pearlman	Project Manager
Ms. Marilyn Schmidt	Director, Office of Democratic and Social Transition USAID/Kyiv

Counterpart International Inc.

Mr. Brian Propp
Mr. Oleg Tartak
Dr. Irina Grishayeva

University of Pittsburgh School of Medicine

Mr. Tom Foley

Fordham University Graduate School of Social Services

Mr. Robert Chazin	Professor of Social Work
-------------------	--------------------------

Children's Hospital of Philadelphia

Mr. William Schwartz	Professor
----------------------	-----------

Overseas Strategic Consulting Ltd.

Drew University

Michael Christensen	Professor of Religion and Psychology
Arthur Pressley	Professor of Psychology

Counterpart International—Kyiv

Dr. Brian Propp	Director CI/Kyiv
Oleg V. Tartak	Deputy Director (CCIP)
Dr. Irina Grishayeva	Clinical Psychologist and Community Outreach Coordinator

Kyiv**Institute of Endocrinology and Metabolism****Zhytomyr****Ukrainian–American Health Center—Zhytomyr**

Dr. Lyudmyla G. Kiriienko	Director
Ms. Alina Bondar	Secretary
Ms. Lyudmila Falkovska	Psychologist
Ms. Angelika Kamenchouk	Psychologist
Ms. Nina Boyko	Psychologist
Ms. Olena Mouzyka	Psychologist
Dr. Igor M. Valouta	Ultrasound Specialist
Dr. Dian Bondar	Director, Oblast Center for Psychosocial Rehabilitation
Ms. Julia Yurchenko	Lawyer, Christian youth union
Ms. Oksana Fedorenko	Psychologist, Christian youth union
Mr. Gleb Genzh	Student, Christian youth union volunteer

Rivne**Ukrainian–American Health Center—Rivne**

Dr. Sergiy R. Rak	Director
Ms. Oksana Shouliak	Secretary
Dr. Mariya V. Doumanovska	Deputy Chief in charge of health care for women and children; Rivne Oblast Health Care Department
Ms. Julia Vetrova	Psychologist
Ms. Veronika Afanasieva	Psychologist
Mr. Andriy Khrapal	Psychologist
Dr. Olena Kovpak	Ultrasound specialist
Dr. Galyna V. Boyko	Pediatric Endocrinologist

Lutsk (Volyn')

Ukrainian-American Health Center—Lutsk

Dr. Grygory V. Vaschylin	Director
Ms. Olena Danylenko	Secretary
Dr. Larysa Liashenko	Ultrasound specialist
Dr. Viacheslav Urizchenko	Ultrasound specialist
Ms. Alla G. Matsiuk	Psychologist
Ms. Oksana V. Mospaniuk	Psychologist
Ms. Antonia P. Melnyk	Psychologist
Ms. Lyubov V. Novosad	Red Cross Nurse
Ms. Julia D. Voytiuk	Red Cross Nurse
Ms. Natalia L. Stankevych	Red Cross Nurse
Ms. Victoria P. Statsiuk	Red Cross Nurse
Ms. Olga Tsymbaliuk	Director, Center of Applied Psychology

Cherkassy

Ukrainian-American Health Center—Cherkassy

Dr. Grygory Ivanovych Borysov	Director
Dr. Petro Levchenko	Deputy Chief, Cherkassy Oblast Health Care Administration
Ms. Olena	Secretary
Dr. Marina Cherniak	Ultrasound specialist
4 psychologists	

ANNEX C
REFERRAL REQUEST FORMS

CHORNOBYL CHILDHOOD ILLNESS PROGRAM PSYCHOSOCIAL REFERRAL REQUEST

Patient Identification Number: _____ ☐ Male ☐ Female Date of Request: _____ Day/Month/Year

Referring Psychologist: _____

Referring Institution: _____

Patient Name: _____ Patient Birth Date: _____ Day/Month/Year

(Family Name), (First Name), (Middle Name)

Address: _____

Oblast: _____ Raion: _____ City/Village: _____ Grade: _____ School: _____

Parents/Guardian: _____

Household Composition: <input type="checkbox"/> mother <input type="checkbox"/> father <input type="checkbox"/> grandmother <input type="checkbox"/> grandfather <input type="checkbox"/> sister(s) _____ <input type="checkbox"/> brother(s) _____ <input type="checkbox"/> other(s) _____ Order of birth: _____	Family History <input type="checkbox"/> f/m died recently _____ <input type="checkbox"/> birth of a sibling _____ <input type="checkbox"/> parents divorced _____ <input type="checkbox"/> f/m married _____ <input type="checkbox"/> other _____	Social History <input type="checkbox"/> family was resettled _____ <input type="checkbox"/> alcohol abuse _____ <input type="checkbox"/> domestic violence _____ <input type="checkbox"/> other _____ Current Family Stressors <input type="checkbox"/> f/m has chronic illness _____ <input type="checkbox"/> f/m(s) unemployed _____ <input type="checkbox"/> financial problems _____ <input type="checkbox"/> other _____
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Clinical Impressions During the Testing Procedure

Problems: <input type="checkbox"/> Extreme shyness _____ <input type="checkbox"/> Nervous, tense or worried _____ <input type="checkbox"/> Fidgety, unable to sit still _____ <input type="checkbox"/> Impulsive and hyperactive _____ <input type="checkbox"/> Aggressive, fights with other children _____ <input type="checkbox"/> Obsessive/compulsive _____ <input type="checkbox"/> Withdrawn _____ <input type="checkbox"/> Shows fatigue _____ <input type="checkbox"/> Looks sad, unhappy _____ <input type="checkbox"/> Somatic complaints _____	Strengths: <input type="checkbox"/> Resourceful _____ <input type="checkbox"/> Focused _____ <input type="checkbox"/> Intelligent _____ <input type="checkbox"/> Curious _____ <input type="checkbox"/> Verbal _____ <input type="checkbox"/> Motivated _____ <input type="checkbox"/> Socially comfortable _____
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CDI Summary: _____

REQUESTED SERVICES

Psychologist Assessment: _____ Individual Consultation: _____ Family Consultation: _____

Surveillance (Follow-up): _____ Further Referral: _____

Appointment time frame requested: _____ Urgent _____ Routine _____

Appointment Date: _____ Time: _____ Location: _____

Referring Psychologist's Signature: _____

Referring Psychologist's Phone: _____ Referring Psychologist's Fax: _____

CONSULTANT'S REPORT: Findings; Diagnosis; Treatment; Recommendations:

Follow-up Visit: _____ Date of Consultation: _____

Signature of Consultant: _____

Printed Name of Consultant: _____ Consultant's Phone: _____

Copy for Physician; Copy for Consultant; Copy to CCIP; Copy for Patient

CHORNOBYL CHILDHOOD ILLNESS PROGRAM MEDICAL REFERRAL REQUEST

Patient Identification Number: _____ ☐ Male ☐ Female Date of Request: _____ Day/Month/Year

Referring Physician: _____

Referring Institution: _____

Patient Name: _____ Patient Birth Date: _____
(Family Name), (First Name), (Middle Name) Day/Month/Year

Address: _____

Oblast: _____ Raion: _____ City/Village _____ Grade: _____ School: _____

Parents/Guardian: _____

REASON FOR REFERRAL

Thyroid Nodule(s) ☐ Thyroid Enlargement ☐ Thyroid Abnormality ☐

Other (describe): _____

NATURE OF PROBLEM

Diagnosis: _____

Symptoms: _____

Clinical Findings: _____

Ultrasound: _____

Psychological Problems: _____

Duration of Findings/Illness: _____ Hospitalization Dates: _____

Medication(s): _____

Allergies: _____

REQUESTED SERVICES

___ Opinion only(no testing) ___ Evaluate and Treat ___ Diagnostic Testing ___ Further Referral to Kiev

___ Other ___ Surveillance (Follow-up) ___ Consultation with Psychologist

Appointment time frame requested: ___ Emergency 0-2 days; ___ Urgent 3-7 days; ___
Facilitated 7-14 days ___ Routine 14+

Appointment Date: _____ Time: _____ Location: _____

Referring Physician's Signature: _____

Referring Physician's Phone: _____ Referring Physician's Fax: _____

CONSULTANT'S REPORT: Findings; Diagnosis; Treatment; Recommendations: _____

Follow-up Visit: _____ Date of Consultation: _____

Signature of Consultant: _____

Printed Name of Consultant: _____ Consultant's Phone: _____

Copy for Physician; Copy for Consultant; Copy to CCIP; Copy to Patient

ANNEX D
SCOPE OF WORK

SCOPE OF WORK
Mid-Term Activity Evaluation
Chornobyl Childhood Illness Program
(CA 121-A-00-98-00608-00)

I. A. Purpose

The contractor will provide an objective mid-term evaluation of the Chornobyl Childhood Illness Program implemented by the Medical Service Corporation International (MSCI) and prepare a written evaluation report for submission to the Ukraine Ministry of Health, USAID/Washington, USAID/Kiev, and MSCI.

The overall goal of the evaluation is to review the work that was done to date and to assess its effectiveness. The specific purposes are to: 1) identify results to date through activity/process indicators, as well as health indicators; 2) determine progress towards achieving specific objectives of the Cooperative Agreement of May 1998, work plans, and 3) relate these to USAID/Kiev's Strategic Objective (SO) 3.2b results framework and indicators for the health sector. Also, the evaluation team will identify: 4) whether the project is in a position to reach their own established objectives; 5) problems/constraints, if any, to the successful achievement of the project's objectives; 6) gaps or areas in need of further work in order to strengthen the project; and 7) formulate recommendations on potential changes.

B. Background

The United States government is concerned about consequences of the Chernobyl power plant disaster in 1986. Through USAID, it sponsors a package of health programs to mitigate Chernobyl's aftermath. A Congressional earmark has aimed \$5,000,000 "for screening and treatment of childhood mental and physical illnesses related to Chernobyl radiation." The increase in the incidence of cancer and psychological problems associated with surviving the accident was of particular concern. The fear of birth defects in the regions affected by the Chernobyl accident has resulted in a sharply lower birth rate. The Congress of the U. S. A. urged USAID to support programs to reduce birth defects and register birth defects among children in affected regions - FOREIGN OPERATIONS, EXPORT FINANCING, AND RELATED PROGRAMS APPROPRIATION BILL, 1997 [Senate Rpt.104-295]. Following Congressional directives, \$4 million was awarded through a competitive process to MSCI for the Chornobyl Childhood Illness Program. \$750,000 was allocated for the Birth Defects Surveillance and Prevention Program in Ukraine being implemented by the University of South Alabama.

The international scientific and medical communities continue to debate a wide range of possible health sequelae from the Chernobyl accident. The probable increase in the incidence of breast cancer, birth defects, leukemia, and immunodeficiency are among disorders, which might be attributed to the Chernobyl aftermath. So far, a sharp increase in thyroid cancer in children has been confirmed. In addition, there is a general

consensus on the substantial psychological damage that the disaster has caused to children and their families. The majority of the population with the highest risk for thyroid cancer lives in six mostly rural northern regions in Ukraine. Stationary ultrasound screening, currently recognized as the main tool for thyroid cancer detection at its earliest and effectively treatable stages, is available in the largest regional population centers, but is not practically reachable by children living in outlying villages. Current economic constraints do not allow local medical facilities to develop expanded screening programs to cover those children. A community-based network for psychosocial services has been practically nonexistent in Ukraine. The implementation of a modern, cost effective, sustainable program for thyroid cancer and psychological screening or early disease detection in treatable stages is of potentially great help to victims of Chernobyl.

In 1998, a Health Strategy was prepared and approved by the USAID/Kiev Mission to strategically guide its future assistance to Ukraine in the health sector. The goal of the Strategy is to assist Ukraine in reforming primary health care, improving the capacity of health practitioners to effectively and efficiently provide community-based health services. Well-organized focused screening program is an important component of primary health care based on prevention, early detection, and appropriate basic care. Psychosocial support adds a needed dimension to a primary health care service. As such, these activities apply to and bolster the favorable outcomes of Strategic Objective 3.2b as part of its Intermediate Result 3.2b.1: Provision and utilization of primary health care services improved.

C. Activity To Be Evaluated – Objectives, Strategy, Accomplishments to Date

The three-year Chornobyl Childhood Illness Program (CCIP) was authorized between USAID and MSCI in May 1998. MSCI is a managing partner of a consortium of organizations. Numerous Ukrainian counterparts are involved in the program. CCIP seeks to improve the access to and quality of thyroid cancer and psychosocial trauma screening, diagnosis and treatment. It has focused on enhancing the cost-effectiveness and sustainability of providing thyroid and psychological care. The project is primarily active in three (of six) most radioactive contaminated regions in Ukraine – Volyn, Rivne, and Zhytomir Oblasts. The Cherkassy Oblast was chosen as the forth-pilot region since a lot of families were relocated to Cherkassy having been forbidden to reside heavily radioactive contaminated zones.

Using a holistic approach to the management of children with physical and mental problems, the MSCI team has elaborated an integrated development approach to address project objectives. The project emphasis is on enhancing thyroid cancer and psychological services in both preventive and therapeutic care. The major actions have reinforced outreach screening modalities for early cancer detection in more treatable stages utilizing clinical and ultrasound examination. Psychosocial problems in children and their families have been addressed through implementation of trauma manifestation outreach screening programs. Activities have also included assistance in the screening database system implementation.

During the first year of implementation, the project has:

- *Conducted detailed needs assessments and identified possible pilot sites in radioactive exposed regions in Ukraine.* The size and location of the target population, that is children between the ages of 12 and 18, was defined.
- *Improved the management of thyroid cancer and psychosocial trauma.* The Policies and Procedures Manual is ready for final review by Ukrainian partners. The manual contains thyroid and psychosocial screening protocols and administrative guidelines for project implementation. Refresher training programs have been provided for physicians and psychologists from pilot regions in ultrasonography, computer applications, and psychological screening tools. Screening data collection and analysis tools have also been developed. The revision of a referral system for patients with thyroid cancer was initiated. Modified treatment protocols have been shared with Ukrainian counterparts.
- *Implemented system changes in thyroid cancer and psychological screening provision.* Memorandums of Understanding (MOU) have been signed with two Regional Health Administrations. Under these MOUs, the Ukrainian-American Health Centers were established and equipped. Each Center will serve as a home base for a mobile screening team and a focal point for a regional screening program. Portable ultrasound and other diagnostic capabilities have been purchased to outfit several minivans, which will be used by CCIP members to visit rural areas and perform screening and diagnostics on a regular basis. A mobile team consists of a physician trained as an ultrasonographer, a psychologist, and a computer operator/driver. Initiated training programs for community psychosocial and health education programs.

The project has provided training to approximately 240 Ukrainian specialists on thyroid cancer and psychosocial screening and case management. Thyroid cancer and psychological screening programs have been launched in the Volyn and Rivne regions. Approximately 2000 children have been examined and 70 children, or 3.5%, have been found to have thyroid abnormalities (through December 17, 1999). During the second year, the program will expand screening programs to additional two pilot regions.

D. Objectives of the Evaluation

The Contractor will:

- Identify, quantify and document the outputs, the results to date of the Chornobyl Childhood Illness Program, including success stories and lessons learned, according to objectives of the project (as stated in the Cooperative Agreement, work plans), as well as in relation to the applicable goals under Strategic Objective 3.2b;

- Assess the Chernobyl Childhood Illness Program impact, if any, and identify factors contributing its effectiveness, not only including current changes in performance/results, but also those institutional changes that laid the basis for future results; and provide this against cost benefit analysis;
- Identify potential linkages with other USAID health programs, and other international donor programs;
- Identify the potential for roll-out and national sustainability of the system changes developed and tested in pilot sites;
- Identify problems/constraints, if any, to the successful implementation of the project, as well as gaps or areas in need of further work in order to strengthen the project and achieve its objectives;
- Recommend possible effective strategies and potential changes of the project implementation for subsequent years.

E. Methods & Specific Tasks

Prior to commencing field work, the contractor will:

A. 1) Collect and review background documents in collaboration with the USAID/Kiev Mission, USAID/W/E&E/EEUD, MSCI. Those documents should include:

- The Cooperative Agreement with MSCI to implement the Chernobyl Childhood Illness Program in Ukraine;
- Other authorizations and/or related project identification documents, and any sub-contracts;
- Work plans, periodic and special reports/trip reports of MSCI, its staff in Ukraine, and any sub-contractors;
- Other referential or historical documents.

The Contractor will utilize existing documentation, local experts, secondary project information, data studies, project documents and interviews to obtain further information.

The USAID Mission will furnish the following documents prior to start-up of fieldwork to assist in the evaluation process:

- 1998 Ukraine Health Strategy
- Strategic Objective Performance Indicators
- Results Tree
- MSCI background documents

2) Identify key stakeholders and beneficiaries in collaboration with MSCI and USAID/Kiev. This group should include the USAID E&E Bureau, Kiev Mission,

MSCI staff, consultants, subcontractors, Ukrainian professionals who participate in the project – deputy ministers, regional health administrators, and health care workers in pilot sites (participants and trainees), and other beneficiaries.

- 3) Prepare and submit a concise written work plan to USAID/Kiev, describing the specific activities to be undertaken, including site visits and a timeline, and indicators to be used to assess the effectiveness of the program;
 - 4) Provide a brief overview of what is currently known of the Chernobyl accident's health consequences, as well as commentary on current health care service delivery for child Chernobyl victims as part of the work plan;
- B. Conduct interviews with relevant staff associated with the project at MSCI and subcontracting organizations, USAID/EE. MSCI staff will meet with the team to answer questions as needed, but will not accompany the team on meetings with government and non-government representatives both in the U.S. and Ukraine.
- C. Obtain country clearances for the team members through the USAID/Kiev Mission and the U.S. Embassy in Ukraine.

During field work, in coordination with USAID/Kiev, the contractor will conduct an extensive review of the work carried out as of the time of this evaluation by MSCI in order to assess progress towards the objectives and effectiveness of the project strategy:

- a) Set up in-briefing session with USAID representatives in the field upon arrival. Interview Kiev-based representatives of the key stakeholder groups, e.g., MSCI staff in Ukraine, USAID/Kiev program managers, relevant Ministry of Health officials, thyroid and psychological care providers, including those trained under the Chernobyl Children Illness Program, patients, and other key beneficiaries and stakeholders. The interview will enable the Contractor to understand better what has transpired during the project, the issues of concerns to all stakeholders.
- b) Conduct site visits, including setting up interview and small working group sessions with host country counterparts; attending previously planned workshops or conferences on the “primary focus” activities.

The evaluation team will analyze the information collected, including the development of clear and specific findings, conclusions, lessons learned and recommendations for potential changes in the program implementation. The evaluation team will conduct an out-briefing session at USAID/Kiev beginning with the presentation of the outline of the findings. The goal of this session will be to reach clarity on the evaluation findings and conclusions. The team should also identify the areas of consensus and divergences, explaining the latter to the degree possible. Lastly, the team should suggest future efforts for improvement of the USAID/MSCI Chernobyl Childhood Illness Program.

The Contractor will write the draft final report of the overall evaluation conclusions, including recommendations for future potential changes which will be reviewed by key USAID/Kiev Mission staff. A copy will be given to MSCI. USAID and MSCI will be expected to provide comments on this report.

After receipt of these comments, the Contractor will issue a final report.

The contractor is responsible for the results of this evaluation, including any need to modify the evaluation design, which may emerge once the task order has begun. The contractor will ensure that USAID/Kiev agrees with any changes in this SOW. No change in the overall level of effort or task order total is possible without written concurrence by the Contracting Officer.

E. Time line

See Attachment A

F. Deliverables

- A. Work Plan: The Contractor will submit a draft work plan for the evaluation process to USAID/Kiev project management for concurrence. The contractor will be required to maintain regular contact with the USAID/Kiev during the planning and execution of the evaluation.
- B. Benchmark indicators: The Contractor shall submit measures/evaluation tools for assessing the impact, effectiveness, and efficiency of MSCI's activity to USAID/Kiev prior to the field work, for approval.
- C. Debriefing: Upon the end of the field visits, the Contractor will provide a debriefing to the Kiev Mission Health Team and management, and a draft final report including the overall evaluation conclusions and recommended next steps.
- D. Report: A final report should include an evaluation of results to date, and a synthesis of lessons learned. Also include a set of recommendations for potential changes, if needed. Ten total copies of the report will be submitted to USAID/Kiev (5 copies) and USAID/W (5 copies). The final report will contain a three to five page executive summary and will not exceed 30 pages plus annexes not to exceed 30 pages.

Specifically, the report should:

- 1. Provide assessment of the performance set forth in the Cooperative Agreement.
- 2. Identify results to date and /or successful activities and accomplishments, or lack of, through activity/process indicators, as well as health indicators.
- 3. Evaluate the effectiveness and impact in relation to specific project objectives

- and Strategic Objective (SO) 3.2b.
4. Identify problem areas/constraints, if any, and address any issues raised by the stakeholders.
 5. Identify, in order of importance and urgency, MSCI activities which should be modified or discontinued, with justifications that support these recommendations.

G. Team Composition

USAID/Kiev is requesting the services of three professional consultants to evaluate the Chornobyl Childhood Illness Program, and a local administrative assistant. All team members should possess superior written and verbal communication skills. Fluency in Russian or Ukrainian is desirable, but not required. Preference will be given to a team with relevant regional and developmental experience. The team leader must have experience with design and implementation of complex evaluations. One consultant must have a strong background in thyroid care, and another in psychosocial problems management. The administrative assistant/logistical coordinator should be someone experienced in local health care system and in working with international organizations. He should provide logistical support by setting up meetings, facilitating interviews, as well as arranging transportation, hotels, and other arrangements, as needed. The primary health or international health consultant should have experience with participatory methods, or should be open to using participatory development approaches for the evaluation work.

The Contractor will certify that there is no conflict of interest with respect to the performance of this evaluation on the part of the contractor and each team member for this evaluation. The Contractor will guarantee that substitutions will not be made for individuals selected as team members without the approval of the designated SO 3.2b Health Core Team representative/Health Activity Manager, USAID/Kiev.

II. TECHNICAL DIRECTIONS

Technical directions during the performance of this task order shall be provided by the Technical Officer as stated in Block 5 of the cover page pursuant to Section F of the contract. The team will conduct its evaluation under the technical guidance of USAID/Kiev and is requested to keep the Mission fully apprised of progress. The evaluation is intended to be forward thinking, constructive and collaborative. While assuring confidentiality, the contractor is requested to keep the lines of communication open and candid.

IV. KEY PERSONNEL

- | | | |
|----|------------------------------------|-----------------|
| a. | Team Leader/Evaluation Specialist | Ted Green |
| | Thyroid Cancer Specialist | Jerome Hershman |
| | Psychosocial Management Specialist | Kenneth Suslak |

ATTACHMENT A**Midterm Activity Evaluation
Chernobyl Childhood Illness Program**

1-5 September	Team reviews background information and documentation, interviews US-based program personnel.
5 September	Team Leader submits draft work plan to USAID/Ukraine CTO.
6-8 September	Team Leader works via electronic communications with a local logistics coordinator and USAID/Kiev CTO to plan evaluation activity and refine work plan: schedule meetings, site visits in Kiev and pilot regions.
9 September	Team Leader, Thyroid Cancer Specialist and Psychosocial Management Specialist depart for Ukraine.
11 September	Team Leader and Logistics Coordinator brief Thyroid Cancer Specialist and Psychosocial Management Specialist/Conduct ½ day team building. Team meets with USAID/Ukraine CTO.
12-16 September	Team makes field visits to Zhytomir, Volyn and Rivne in one field trip.
18 September	Team makes field visit to Cherkassy.
19-20 September	Team visits stakeholders in Kiev.
21-22 September	Team performs fieldwork analysis.
23 September	Thyroid Cancer Specialist departs for US.
25 September	Team presents key findings and recommendations and draft report to USAID/Ukraine
26 September	Psychosocial Specialist and Team Leader depart for US.
2-6 October	Final report preparation.
20 October	Receive final comments from USAID/Ukraine and stakeholders.
3 November	Submit final report to USAID.